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UNIVERSITY OF ALBERTA

**The Experiences of Caregiving and Social Support Among Family Caregivers of Aids  
Patients: A Zimbabwean Case Study**

by



**Edward Makwarimba**

**A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND  
RESEARCH IN PARTIAL FULFILMENT FOR THE DEGREE OF  
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UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommended to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **EXPERIENCES OF CAREGIVING AND SOCIAL SUPPORT AMONG FAMILY CAREGIVERS OF AIDS PATIENTS IN ZIMBABWE** submitted by **EDWARD MAKWARIMBA** in partial fulfilment of the requirements for the degree of **MASTER OF SCIENCE**.



## **Dedication**

To my daughter, Rejoice, whose impatience when we could not play together, spurred me on.

To all caregivers of PWHA who are surviving under the most difficult circumstances, particularly those that took part in this study, your emotive experiences and contribution to knowledge will forever be remembered.



## ABSTRACT

This exploratory study sought to describe the social context and lived experiences of family caregivers of AIDS patients in Zimbabwe, with a special focus on the informal and formal supports received. Multiple interviews were conducted with purposively sampled, low-income caregivers, and volunteer home-based care workers. Ethnographic and phenomenological methods were used to analyse the field notes and interviews.

Formal supports from the government and non-governmental organizations were found inadequate and uncoordinated. Prejudice and stigmatisation result in rejection and ostracism of caregivers and patients, leading to social isolation and loneliness, and reduced social support. Most of the caregivers experienced role-overload and role conflict from the combination of caregiving responsibilities, household chores, and income-generating activities. These findings point to the need for far-reaching and upstream interventions that tackle issues of unemployment, poverty, and AIDS, through participatory involvement, a strategy likely to strengthen social networks and provide supports and livelihood resources.



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## CHAPTER I

### INTRODUCTION

Zimbabwe is one of the countries worst hit by the AIDS pandemic in the world. By 1998, it was estimated that 800 000 people, out of a total population of 12 million, were HIV-infected (Zanamwe et al., 1998). Bed occupancy rates in 1994/95 of the two major hospitals in the capital city had over 70% of the patients admitted with HIV infection (Zanamwe et al., 1998). Medical and hospital services are increasingly strained, because of escalating caseloads due to AIDS and also because of fiscal retrenchments due to the IMF-driven economic adjustment program. The costs of formal home-based care in Zimbabwe, initially developed in response to rising costs of hospital care, chronic shortage of beds, and the limited benefits of hospitalisation, are considered high and restrictive, resulting in most of the care being performed by family caregivers.

Increased AIDS cases translate into more family caregivers taking care of these patients (Zanamwe et al., 1998). Much of the caregiving for discharged AIDS patients falls on women, because the culture supports this social arrangement of care giving responsibility (Mushonga, 1998). For poor rural women, already burdened with childcare and agricultural production for survival, caregiving adds another burden to these social roles. The situation is also worsened by the fact that most people with AIDS/HIV (PWHA) in towns are readily absorbed back into their kin's rural households, to be cared for by female family caregivers.

People with AIDS also live in communities full of social stigma surrounding HIV positivity and AIDS (Mutetwa, 2000; The Herald [Zimbabwe], May 18, 2000; Busza, 1999; Kalondo, 1996; Hwayire, Sibanda & Phiri, 1996; Anderson, 1994; Cassidy, 1990; Kadushin, 1996; Bourgon & Renaud, 1990) and those who care for them, the world over. This phenomenon has been observed in Africa as a whole (Anderson, 1994; Kalondo, 1996), and in Zimbabwe (The Herald [Zimbabwe], May 18, 2000; Mutetwa, 2000; Hwayire et al., 1996). These social stigmas lead to social isolation and loneliness for PWHA and their caregivers (Casaux & Reboreda, 1998, Hwayire et al., 1996).



A central assumption of this thesis is that caregivers undergo the same stresses and isolation as PWHA. Social isolation, in turn, can lead to emotional and physical health problems (Rook, 1985). These arguments suggest that social support might facilitate coping with the stress associated with caring responsibilities, thus alleviating social isolation and enhancing the health of caregivers. Since “health status and health behaviour depend on individual and group ability to interpret, manipulate, and cope with environmental stressors” (Stewart, 1989, p.1276), a network and social support intervention would be more likely to empower especially female caregivers, who are already part of a marginalized segment (i.e. women) in Zimbabwean society. Social support would bolster their self-esteem and a sense of environmental mastery.

The discovery of new medications for AIDS-related diseases, improvements in palliative care, and widespread general knowledge regarding care of PWHA tends to make them live longer, thus prolonging caregiving duties for family caregivers, and spreading the attendant psychosocial stresses over a longer time period. Over time, society ends up with more caregivers of PWHA, suffering from psychosocial problems, and deserving appropriate social support, provided measures to determine their needs have been put into place.

### **Statement of Problem and Purpose**

As the AIDS pandemic wreaks havoc in Zimbabwe, much effort has initially gone into preventive health education, and the current focus of the Ministry of Health and Child Welfare is on providing support to people with HIV and AIDS through home based care and helping them establish networks. There is a realisation that family/informal caregivers of persons with HIV/AIDS need social support; however the focus is restricted to facilitating their caregiving role through informational support.

This study sought to expand the focus on social support to caregivers to enable them to cope with the stresses attendant to caregiving and to help them improve their quality of life, in addition to strengthening their caregiving knowledge and skills. This was achieved by documenting the lived experiences of caregivers in a manner that highlighted the types of supports necessary for their caregiving and other family roles.



The pertinence of such an approach is underscored by the dramatic increase in the number of AIDS cases in Zimbabwe, which will increase demands placed on female family caregivers. If health (or well-being) is considered a basic human right (WHO, 1992; Cook, 1994, Jarkata Declaration, 1998), regardless of gender (Cook, 1994), then a proactive approach to improving the quality of life of women would be a major step towards the achievement of social equality.

## **Significance**

Since the majority of family caregivers are women, the knowledge that was obtained from this study is hoped to generate ways of empowering women through provision of support with the potential goal of improving their quality of life. The study also generated information that could be used to strengthen social ties and social networks (through different ministries and governmental organizations) in order to develop and enhance social capital in local communities, which could help enhance the benefits of investment in physical and human capital that are the engine of development.

Since there is a paucity of research in the area of social support (especially support for family/informal caregivers), in developing countries, the findings from this study can elucidate our understanding of the meanings of social support from a different cultural perspective, and hopefully, this understanding will spawn further research by others. The findings are also expected to generate hypotheses to guide subsequent research.

## **Research Questions**

The research addressed a number of questions, including: What do family/informal primary caregivers of AIDS patients consider to be their foremost concerns? How do they cope with these concerns? How would they want these concerns addressed? What are the barriers (cultural, socio-economic, personal) to receiving and utilizing formal and informal supports? Which of these factors make it easier to receive and utilize supports? Is the traditional family network a major resource to fall back on for support in the face



of social stigma attached to AIDS? Have the present economic hardships caused by the introduction of the economic adjustment programme (in 1990) affected the flow of resources in social networks? Have these economic hardships affected the way social support is reciprocated? Are caregivers satisfied with the formal and informal supports they receive and supports they perceive to be available? Do they wish for more social support? If so, from who? Which kinds of supports are most beneficial in which situations? Does the receipt of, and satisfaction with support depend on gender, marital status, age, or geographical area (rural or urban)? What are the critical points of the trajectories of the caregiving process that may serve as a basis to develop support programmes? These are the primary questions that were addressed by this study.

### **Research Objectives**

This study sought to explore the lived experiences of family caregivers of AIDS patients with formal and informal informational, emotional, esteem, instrumental supports. Therefore, the study specifically sought to:

- a) understand sources of stress for family/informal caregivers of AIDS patients.
- b) explore the coping styles of family/informal caregivers of AIDS patients.
- c) assess self-identified barriers family/informal caregivers face in obtaining formal and informal support.
- d) develop an understanding of the formal and informal support needs of family caregivers.
- e) distinguish which kinds of help are most beneficial in particular situations.
- f) match the perceived burden of caregivers with their perceived adequacy of social support.
- g) obtain caregivers' levels of satisfaction with the support they receive and support which they perceive to be available.
- h) understand and document the cultural expectations that dictate the appropriateness, acceptance and utilisation of different types of supports from different sources.



- i) understand and document the social distribution of support by noting how it varies across sub groups of caregivers (i.e., by marital status, gender, age, rural-urban divide).
- j) understand the nature and adequacy of ‘administered support’ from the perspective of formal support providers.
- k) document the caregivers’ subjective evaluation of their health/well-being.

### **Policy Relevance**

In this time of fiscal retrenchments in Zimbabwe (affecting the non-productive sectors such as social services) due to the economic structural adjustment programme (ESAP), the government will be better informed about the importance of interventions aimed at providing social support to informal caregivers. These interventions, aimed at strengthening the resilience and coping mechanisms of those caring for AIDS patients, would be an extension of, or a parallel effort to work in synergy with, the current efforts to control AIDS.

The comparative nature of the study emphasizes the importance of understanding the distribution of social support in different communities and across subgroups. This will make it possible to future policy initiatives to target or incidentally influence social support.

Finally, it is also hoped that the knowledge generated from this study will also be useful for the planning of home-based care programmes, including the training of home-based care workers so that they attend to the specific support needs of caregivers.

Baylies (1999) underscores the importance of effectiveness, appropriateness and targeting in the setting of priorities for resource allocation in respect of AIDS interventions. This is a laudable call, and it is hoped results from this study will go some way towards enabling such policy measures.

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## CHAPTER II

### LITERATURE REVIEW

#### Introduction

In all parts of the world, initial efforts to deal with the AIDS epidemic focused on changing people's sexual behaviours (especially among at-risk populations) through abstinence and use of condoms with somewhat limited success in some parts of the world and within some sections of the population. Given the enormity of this pandemic, early efforts also went into public programmes for counseling, testing and teaching people about HIV and how it is transmitted (Fishbein and Guinan, 1996). School based HIV education programmes to reduce sexual risk behaviours (Fishbein and Guinan, 1996; Kirby et al, 1994) also became popular.

Focus then shifted to providing support to those that have contracted the disease, because they face the prospect of chronic, debilitating illness and early death. Many of them will also face the challenge of coping with emotional ramifications of their disease as they tend to have high levels of depression, maladaptive coping with HIV infection, and social isolation. Some of the commonly used interventions within behavioural medicine (Nicholas and Webster, 1996) and health psychology (Kelly et al., 1993; Reemer et al., 1998; Lutgendorf et al., 1998) traditions are psychotherapy, educational support groups, and cognitive behavioural therapy.

Efforts to provide social support to persons with HIV infection have normally revolved around using social support groups (for example, Kelly et al., 1993; Lutgendorf et al., 1998) or individual interventions (for example, Gustafson et al., 1999; Rounds et al., 1999), two of the most widely used approaches (Gordon, 1993). Because of the exponential growth in the number of cases and the lack of a cure and definitive treatment, strategies aimed at preventing transmission and maintaining the overall well-being of those already infected become increasingly important.

Much of the research that has looked into caregiving regards it as a stressor, and has documented the negative impact caregiving has on caregiver health and well-being (Rosenthal, Sulman & Marshall, 1996). The caregiving role is therefore associated with feelings of burden, fatigue, depression, anxiety, negative affect, and low morale.



According to Rosenthal, Sulman & Marshall (1996), caregivers face competing role responsibilities that render them more susceptible to negative outcomes. In as much as efforts have gone into helping caregivers of people suffering from other chronic diseases, efforts have recently shifted to encompass social support for caregivers of PWHA. This chapter will, first of all, discuss social support, what it is, and its place as determinant of health. Next, the chapter discusses the relationship between social support and social networks, the prevalence of AIDS in the world and in Zimbabwe after which a review of literature on social support empirical studies and interventions is undertaken. The chapter closes with a discussion of the weaknesses of these studies and interventions, and outstanding research issues.

## **Social Support**

From the 1970s, when research on social support began, the major goal has been to guide novel preventive and treatment interventions (Lakey & Lutz, 1996). Various definitions of social support have been postulated, depending on one's discipline, theoretical perspective, as well as focus (i.e. individuals or social networks). For example, social support has been defined by Cobb (1976, in Nunes et al., 1995) as the individual's belief that he or she is cared for and is a member of a network of mutual obligations. A fairly similar definition is given by Sarason, Levine, Basham and Sarason (1983), as the existence or availability of people whom we can rely on, people who let us know that they care, value and love us. On the other hand Thoits (1986: 417), from a social psychological perspective conceptualises social support as "...coping assistance, or the active participation of significant others in an individual's stress-management efforts."

Basically, one has to feel that they are being cared for and loved, valued and esteemed, able to count on others (in the network) should the need arise. In this study, however I used Stewart's (2000: 85) definition, which takes social support to be "...interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and emotional help."



Social support is a multidimensional (Richman et al., 1993; Pierce et al., 1996; Sarason, Pierce & Sarason, 1990) or omnibus (Green, 1993) concept reflecting different aspects of social relationships. Consequently, there is lack of consensus regarding how it should be conceptualized and operationalised. Each study devises its own measures to suit its focus (Green, 1993; Kadushin, 1996) and, often little attention is paid to the interconnections between the elements (Pierce et al. 1996). And this has resulted in the use of models that lack strong empirical support (Lakey & Lutz, 1996).

One controversial research area concerns the constructs of social support. For example, in a literature review, Kadushin (1996) found social support to be generally subdivided into three concepts, viz. integration, social network, and relational content. The first involves quantity of social relationships, such as the number of friend or relatives and the frequency of contact with these. The greater the quantity the more one is seen as being embedded in a social network.

Another body of research identifies a different set of three concepts, viz. social embeddedness, perceived social support and enacted social support (Streeter & Franklin, 1992). The first one refers to actual connections people have to significant others in their environment and, the focus is on social networks. Others (e.g., Dunkel-Schetter & Bennett, 1990) distinguish four types of support, namely emotional, tangible, cognitive-informational, and directive guidance. Regardless of these inconsistencies, however, social support is generally considered an interpersonal transaction that involves emotional concern, instrumental/practical aid, information, or appraisal and affirmation (House, 1988, in Stewart et al., 2000).

Despite differences in definitions of social support as well as constructs used in different studies by different scholars, there seems to be no dispute over the fact that there are two broad views of social support. The first is a situation-specific view in which social support is tied to coping with a particular stressful event and, a developmental approach in which social support is seen as a contributor to increased sense of control over destiny, growth-enhancement, personality and social development (Minkler, 1998; Pierce et al., 1996; Israel, Checkoway, Schultz & Zimmerman, 1994; Barrera & Ainlay, 1983). The three common dimensions of social support therefore are, structure, function, and appraisal (Stewart et al., 2000, Stewart, 2000; Stewart & Langille, 2000).



## Structure and Functions of Social Support

The structure of support encompasses the various sources of support. These include lay (such as partners/spouses, family members, friends, neighbours, co-workers, volunteers, and self-help mutual aid groups) and professional sources (such as health professionals; Stewart, 2000; Stewart & Langille, 2000). Hence structural measures of support assess such characteristics of social involvement as how many friends an individual has, how often thee friends are seen, whether or not the individual is married, and so forth (Rook, 1985). According to Sarason, Pierce & Sarason, 1994), those that put emphasis on interpersonal connectedness in their definition of social support tend to investigate the structure of one's network. In this case, structural features of a network, such as size, composition, and density or interconnectedness of members are investigated, with particular attention to how they influence the impact that social interactions have on network members.

The actual giving, receiving and exchange of support are commonly referred to as the functions of social support (Antonucci, 1985; Rook, 1985). A functional approach seeks to specify those aspects of social support that are beneficial to individuals who are experiencing specific types of stressful events (Cutrona & Russell, 1987, in Sarason, Pierce & Sarason, 1994). The approach also posits that support needs vary with stressors and situational factors but fails to look into the sources of support and the interpersonal context of social provisions (Pierce, Sarason & Sarason, 1990, in Stewart & Langille, 2000; Sarason, Pierce & Sarason, 1994). Out of several classifications, two broad functions of social support can be identified, namely, instrumental and affective (Streeter & Franklin, 1992). The former addresses tangible forms of support (e.g., material aid and financial assistance), and the latter include emotional support, social reinforcement, recognition and esteem building.

Other scholars have generally broken these classifications into four functions. For example Wills (1985) has given the four functions as: esteem support (which increases feelings of self esteem), informational support (involving providing necessary information, advice, and guidance), instrumental support (defined as providing assistance with instrumental tasks, and also termed aid, tangible support, or material support), and social companionship (which involves various kinds of social activities). However, the



four functions commonly found in the literature are emotional (encouragement and reassurance), instrumental (practical), informational, and affirmational (feedback) (cf. Stewart, 2000; Stewart & Langille, 2000).

### Appraisal of Support

There is a general and important distinction (elaborated below) between supports perceived to be available from one's social network and support that is received. According to Stewart and Langille (2000:7) received support is appraised or evaluated with respect to direction and to drawbacks or benefits. In other words, it is important to look into the nature of reciprocity in support exchanges as well as trace benefits and costs to both recipients and providers of support. Apart from the drawbacks, benefits, and direction, support is also appraised or evaluated with respect to its duration (Stewart, 2000).

### Stress, Coping and Health

Stress "...occurs when the demands posed by negative environmental occurrences exceed the present coping abilities and resources of an individual" (Wills, 1985: 65). It is also largely linked to mental health. And coping refers to "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" Lazarus & Folkman, 1984, in Thoits, 1986: 417). "Coping helps people to manage stressful situations associated with chronic conditions and caregiving" (Stewart & Langille, 2000: 11). According to Wills (1985), the consequences of stress appraisal include lowered self-esteem, perceptions of low self-efficacy, and perceived lack of control over important events.

Empirical evidence abounds that links social support to good health, particularly physical and mental health (Jankowski et al., 1996; Lakey & Lutz, 1996; Ryan & Solky, 1996; Kadushin, 1996; Stewart & Langille, 2000; Stewart, 2000; Turner & Marino, 1994; Richman, Rosenfeld & Hardy, 1993; Flaherty & Richman, 1989; Israel, 1982), and the relationship between social support and health is reported to be bi-directional (Stewart,



2000; Stewart & Langille, 2000). This is because "health and illness [also] affect availability and quality of social support", for example, "illness can be a major stressor involving loss of...relationships", among other things (Stewart, 2000: 95). Social support has also been found to influence health outcomes of caregivers (Stewart & Langille, 2000).

While social relationships and the flow of resources from one's social network maintains health, facilitates recovery (Bloom, in Stewart & Langille, 2000), and reduces mortality, stressful social relationships can prolong physical dysfunction (Kaplan & Toshima, in Stewart & Langille, 2000). Hence, the relationship between social support and health is not always positive, because constructs of social support sometimes also lead to negative psychological and physical outcomes (Sarason, Pierce, and Sarason, 1994).

Research has shown that social support can restore or enhance role functioning, reinforce existing social structures, enable successful coping with stressful situations, and alleviate social isolation (Stewart, 2000; Stewart, Hart & Mann, 2000; Stein, 1991; Maguire, 1991; Heller, 1990; Stewart, 1989). Some scholars have found a reciprocal relationship between support and coping. For example, Gottlieb talks of supportive persons altering appraisal of stressors, sustaining coping efforts and influencing choice of coping strategies (1988, in Stewart, 2000: 90-1). Conversely, how one copes provides signals to potential supporters about the need and types of support required, if it is required.

From their review of social support literature, particularly its causal relationship with stress, physical and mental health, Sarason, Pierce, & Sarason, (1994) portray a complex picture of this relationship. They argue that the relationship may depend upon circumstances yet unexplored by researchers. For example, they posit that, "...mobilization of support may be weaker for chronic or gradual onset conditions in which caregiver burnout plays an important role than for accidents or sudden-onset diseases" (Sarason, Pierce, & Sarason, 1994:161). Other possible intervening variables affecting the way social support moderates stress health and illness that these authors found in their review of literature are social skills, and personality characteristics, such as introversion or extroversion, that relate to support-eliciting skills. In the Convoy Model



explicated by Antonucci (1985), personal characteristics are also observed to have a determining influence on both the structure and function of an individual's support network.

In what they call a broadened (interactional-cognitive) view of social support that they envision, Sarason, Pierce, & Sarason, (1994) see potential in looking into features of relationships that can influence the impact of social support on health and well-being. Their argument is that, "the effect of support given to individuals varies as a function of providers and recipients' histories of reciprocal supportive relationships" (Sarason, Pierce, & Sarason, 1994: 171). Their conclusion is that, "...although social support alone may play an important role, it also may interact with other individual difference and environmental variables that need to be identified and evaluated" (Sarason, Pierce, & Sarason, 1994: 161). This view is in support of an earlier position by Flaherty & Richman (1989) who argue that there are strong gender differences in both the elicitation and provision of social support.

A good example of the role played by the environment as posited by Sarason, Pierce & Pierce (1994) above can be noted in the assertion by Flaherty & Richman (1989: 1221) that "...gender differences are based on gender specific socialization experiences which are ... perpetuated within adult social roles." Other environmental variables that are possible determinants of an individual's support convoy can be found in what Antonucci (1985: 25) calls 'situational characteristics'. A few examples would be role expectations, opportunities, demands, resources, residence, organizational membership, and life events (Antonucci, 1985). Those scholars that have gone further, to look into the influence of macro-social structures on the processes of social support would also argue that it is "...conditioned by differences in social experience and /or contemporaneous life circumstances" (Turner & Marino, 1994: 194). This focus leads to comparative research in which structural variables, such as socio-economic status (SES), marital status, sex, gender and age are put on the agenda (Turner & Marino, 1994).

Despite the different conceptualizations and operationalisations of social support, the underlying theme through much of the work is the concern with how help from one's social network helps them get through stressful events. Also, despite the raging debates surrounding the link between social support and well-being, social support is still



generally considered a protective factor in resilience (Stewart, Mangham, & Reid, 1997), a resource for coping (Thoits, 1995; 1985) that influences depression levels (Turner & Marino, 1994), health status, health behaviour and health services use (Stewart, 2000; Bloom, 1990).

Social support has been reported to influence health behaviour (Stewart & Langille, 2000; Stewart, 2000). According to Stewart (2000: 93-4):

Social network members may influence health behaviour directly through motivation or provision of information, and directly through encouragement to comply with regimens or to maintain health behaviours.

Much of the influence on health behaviours are reported as supportiveness, encouragement, and modelling by family members, friends, and co-workers (Zimmerman & Connor, in Stewart, 2000 and Stewart & Langille, 2000). However, the down side is that "interaction with network members may also yield negative outcomes, such as reinforcement of poor health behaviours or diminished self-care" (Stewart, 2000: 94).

Overall, social support has two health effects, main effects and buffer effects (Dunkel-Schetter & Bennett, 1990). "Buffering implies that support protects people from the deleterious effects of stress on health and well-being" (Dunkel-Schetter & Bennett, 1990: 284). However, according to Lakey & Lutz (1996), perceived social support has a higher positive correlation with physical and mental health than objective social support.

### Perceived and Received Support

The exposition of these two concepts, which are largely unrelated (Dunkel-Schetter & Bennett, 1990), is one of the many distinctions made by researchers regarding the nature of social support. In this case, this one is with regard to the functional aspects of social relationships (Dunkel-Schetter & Bennett, 1990). Perceived or available social support "reflects an individual's subjective appraisal that others would provide support if needed, as well a general sense of being loved and valued" (Lakey and Lutz, 1996: 436; Sarason, Pierce & Sarason, 1990; Dunkel-Schetter & Bennett, 1990). This concept views social support as a cognitive appraisal of one's connections to others (Streeter & Franklin, 1992). Measures of this concept recognize that not all linkages between individuals and their environment result in social support.



On the other hand, received or enacted social support "refers to the provisions of specific supportive behaviors under stress, such as advice or reassurance [or assistance]" (Lakey and Lutz, 1996: 436, Streeter & Franklin, 1992). It is also variously known as, objective, experienced/actual or administered support (Dunkel-Schetter & Bennett, 1990). Whereas administered support reflects the provider's perspective, received support concerns the recipient's view, therefore, these terms often used interchangeably do have slightly different connotations.

One important debate raging in the field of social support centers on which of the two is more associated with positive health outcomes. A review by Lakey & Lutz (1996: 437) concluded that, "...only perceived support is related to psychological and physical health." According to Turner & Marino (1994), the bulk of evidence pointing to this relationship has come from studies that have focused upon perceived social support. Dunkel-Schetter & Bennett's (1990) review of studies comparing the health-protective effects of available and received support suggests that "...perceptions of available support moderate the relationship between stress and psychological outcomes and assessments of received support do not" (Dunkel-Schetter & Bennett, 1990: 284).

However, other researchers contend that received support will have a greater influence on health following a stressful event than will available support (e.g., Gottlieb, 1985, in Dunkel-Schetter & Bennett, 1990). Gore (1985, in Dunkel-Schetter & Bennett, 1990:285) also argues that "the question of a stress-buffering effect of social support...is contingent upon evidence that support is mobilized, not that it exists as a potential." In other words, these authors are implying that received support will be more powerful in creating a buffering effect than will available support. It is therefore, Dunkel-Schetter & Bennett's (1990: 289) "...belief that received support is more likely to have buffer effects, whereas available support is more likely to have main effects."

Dunkel-Schetter & Bennett (1990) have put forward two major possible explanations of the discrepancy between available and received support that can render perceptions of the availability of support inaccurate. The first one concerns the judgments about the amounts of support expected. One may either believe that there is more support available than actually materializes in a time of stress, or more support may materialize than was perceived as available. Apart from this, though initial levels of



support may meet expectations, there may be an unexpected decline over time in the extent of support received. The second type of inaccuracy pertains to the quality of support. An individual may believe that close relations and friends are available to provide skilful support when in fact the support received is disappointingly inept and unhelpful (Dunkel-Schetter & Bennett, 1990). Dunkel-Schetter & Bennett (1990) have gone further to outline a number of possible mediators of the discrepancy (outlined above) between available and received support. Some of them are: the severity of the stressor, individual differences (e.g., self-esteem, the propensity to seek help), coping styles and behaviours (e.g., problem-solving, seeking support, positive reappraisal coping, distancing), and social network characteristics (e.g., diffusion of responsibility among network members, degree of intimacy of one's social relationships, the changing nature of social relationships likely to generate conflict, competition, and indebtedness). These contributions make it apparent that the debate on perceived and received support is not settled, just like the one on social support in general.

## Perspectives

A number of theoretical perspectives have been invoked to shed light on interactional processes of support networks in which social support is given and received. Some scholars have used one theoretical perspective, while others have used several in the same study. The choice of perspectives has largely been influenced by the discipline the researcher(s) is/are coming from. The ones that have been frequently used are coping theory, social exchange theory, social comparison, and loneliness theory.

### Coping Theory

Stress models, based on social psychological theory, identify social support as an important resource or coping mechanism that can reduce negative effects of stressors (cf. Dawn & Perrewe, 1999; Thoits, 1986). Hence it is considered a resource for coping (Thoits, 1995; 1985; 1986). In other words, "...social support reduces, or buffers, the adverse psychological impacts of exposure to stressful life events and ongoing life



strains" (Thoits, 1985: 416). In fact, Thoits (1986) has reconceptualised social support as coping assistance.

Stressors or stressful circumstances are defined as the experience of negative life events and chronic life strains (Thoits, 1985). While negative life events are culturally or personally undesirable changes in the usual activities of an individual that require behavioural adjustments, chronic strains are persistent conditions that repeatedly interfere with the adequate performance of ordinary role-related activities (Pearlin, 1983, in Thoits, 1986). Examples are chronic illness and excessive job responsibilities. No doubt, work overload from caregiving responsibilities would be considered under 'excessive job responsibilities'. According to Thoits (1986: 417), empirical studies have established that "...only negative stressors, especially those subjectively rated as undesirable, increase indicators of distress or disorder, [while] positive events have only minor effects on psychological symptoms."

The three major ways of coping with stressors are: problem-focused coping (which consists of direct actions on the environment or on the self to remove or alter circumstances appraised as threatening), emotion-focused coping (which consists of actions or thoughts to control the undesirable feelings that result from stressful circumstances), and perception-focused coping (consisting of cognitive attempts to alter the meaning of situational difficulties so they are perceived as less threatening; Thoits, 1986). Given this scenario, a common ground between coping and social support can be drawn. Problem focused-support and instrumental support are both directed at changing or managing the stressful situation, emotion-focused coping and emotional support each attempt to ameliorate the negative feelings that typically accompany stress exposure, and perception-focused coping and informational support are attempts to alter perceptions of stressful situations (Thoits, 1986). Thoits (1986: 421) goes on to emphasize that "...individuals must perceive empathic understanding in others before coping assistance will be sought and accepted, and that others who are socioculturally or experientially similar to a distressed individual are most likely to be perceived (and to be empathic)."

Therefore, methods to assist persons in dealing with other health related stressors (e.g. chronic illnesses) are being fruitfully applied to the problem of coping with HIV infection. Similarly, these methods could be applied to help caregivers of PWHA cope



with stressors surrounding caring for someone with AIDS and the attendant social stigmas. Most importantly for our study, though, is the application of this perspective to the understanding of how caregivers are presently coping.

### Social Exchange Theory

Others regard social support as one type of social exchange (Flaherty & Richman, 1989), and exchange processes are considered salient in social interaction (Howard & Hollander, 1997). Support can be unidirectional/non-reciprocal or bi-directional/reciprocal (Stewart & Langille, 2000). Since theories of equity and social exchange indicate that support may involve benefits and costs for both recipients and providers, Stewart & Langille (2000) emphasise the importance of looking into the issues of reciprocity in social support research. Reciprocity has long been considered an important element in the functioning of a support network (Kahn & Antonucci, 1980, in Antonucci & Depner, 1982).

Social exchange theory considers exchange processes central to social interaction (Howard & Hollander, 1997); therefore, it boards well with social support research since the analysis looks into interactional processes. The unit of analysis in exchange theory is the exchange relationship, which is taken as "a series of transactions between two or more actors occurring over time" (Howard & Hollander, 1997: 47). The focus is on the circumstances under which certain interaction (or exchange) takes place, not why a person behaves in a certain way. Exchange theory then "...contends that interaction takes place when it is mutually rewarding to the parties involved" (Howard & Hollander, 1997: 47). Furthermore, it considers individuals in a broader social context than social learning theory or behaviourism from which it derives. Hence, "rather than try to explain the nature of a relationship as a result of qualities within the actors, this research explains the qualities of the actors by exploring the nature of the relationship" (Cook, O'Brien, and Kollock, 1990, in (Howard & Hollander, 1997: 49).

Another important aspect of exchange theory is the central model for its view of interaction, which is the economic transaction (Howard & Hollander, 1997). The economic model whereby money is exchanged in return for an item is applied to other social situations. For example job seekers exchange work skills for employment, or,



attractiveness is exchanged for a date with a desirable partner. From this perspective, resources involved in exchange transactions are not just material. However, actors are regarded to be seeking the best possible outcomes from interactions. According to Howard & Hollander (1997), cognition also plays a central part in the theory. Consideration of alternatives and choice are the main forms of cognition. Specifically, when actors are deciding on a course of action they are assumed to weigh the costs and benefits of the available options and choose rationally between them.

However, according to Howard & Hollander (1997), decision-making is not the only important part of cognition. The other factors that influence decision making that are left out in this theory are, for example, "...beliefs, attitudes, and membership in and identification with certain groups (e.g., based on ethnicity, gender, or religion) (Howard & Hollander, 1997: 48).

One of the most useful aspects of social exchange theory is the attention it gives to power as a central mechanism of social interaction. Power is "defined as an actor's ability to achieve a favourable outcome at the expense of another and is a quality of a relationship, not an individual" (Howard & Hollander, 1997: 49). Hence according to Howard & Hollander (1997), one's power over another person depends on the value of one's resources to that other person, together with the availability of those resources from alternate sources. In addition, Homans' (1974, in Howard & Hollander, 1997) 'principle of least interest' predicts that the person who is least dependent on a relationship has the greatest power in it, because that person can more easily abandon the relationship. In relation to this aspect of power is the acknowledgement that power is not a static quality of a person but a dynamic, shifting property of a relationship.

One facet of exchange theory "predicts that persons who receive aid may experience a state of indebtedness, which is perceived as aversive and can discourage further help seeking" (Wills, 1985: 64). However, Clark (1983; Clark & Mills, 1979, in Mills, 1985) argues that in communal relationships, interpersonal behaviour is governed more by a felt desire to respond to one another's needs and less by exchange principles. This is consistent with the position of other investigators who have noted that as close relationships develop, members feel increasingly interdependent and perceive themselves more as a unit than as a set of exchanging parties (cf. Wills, 1985). The above two points



of view make it pertinent therefore, to consider the persuasive argument put forth by Antonucci & Jackson (1990), namely, that the relevance of the cultural context should be considered in the evaluation of social exchanges, particularly the role of reciprocity in how social support operates.

In as much as this study needs to examine issues of exchange processes between caregivers, significant, and others in formal structures, all within a traditional (communal) culture, it is imperative to find out whether the exchange processes are based on exchange principles or a felt desire to respond to family members', friends' or neighbours' felt needs.

### Social Comparison Theory

Work based on social comparison theory has spawned hypotheses regarding the perception and reception of empathic understanding based on sociocultural and situational similarity (Thoits, 1986). On a practical level, sociocultural similarity increases the probability that a significant other will suggest coping techniques or attempt to influence circumstances in ways that are viewed by the individual as acceptable. Therefore, similarity in social background and values reduces the probability that others will offer inappropriate or unacceptable coping assistance (Thoits, 1986).

According to Thoits (1986), similarity of situational experience is more important than sociocultural similarity, but the latter enhances the former. This means individuals are more likely to compare themselves with and affiliate with others who have faced the same stressful circumstances. Hence distressed individuals feel that others who have experienced the same situation are most likely to understand (Gottlieb, 1985, in Thoits, 1986). However, the type of 'miserable' or 'formerly miserable company' chosen depends on two factors that help to streamline the number of those affiliated or compared with. These are two competing comparative motivations known as social comparison for self-evaluation and comparison for modelling of guidance (Thoits, 1986). In this case:

Very calm others may cause distressed individuals to view themselves as inadequate, motivating them to shift comparison to more upset others for evidence of relative superiority. But the desire to reduce distress can turn individuals' attention away from those who are more upset toward calmer others for guidance (Thoits, 1986: 420).



An important point to note is that some situational reactions prompt social avoidance rather than affiliation with others. Thoits (1986) also argues that empathy or sympathy from similar others is a crucial condition for the seeking and acceptance of coping assistance. Others' empathic understanding provides reassurance that emotional reactions are valid and acceptable. Comparatively, because others are familiar with the same feelings in response to the same circumstances, those feelings are given the sanction of emotional convention (Thoits, 1986). According to Thoits (1986: 420), "comparisons with empathic others should reduce self-condemnation for what initially might be viewed by the individual as inappropriate or deviant feelings."

Practically speaking, according to Thoits (1986: 421), "coping aid from others who have faced or who currently face similar stressors and who have experienced similar reactions should be highly efficacious." This is because 'these others' have detailed knowledge of the situation, as well as that from past trial-and-error experience they can recommend techniques that are not only situationally applicable but also are most likely to reduce distress over the long run. Therefore, when empathic understanding is the product of both situational and sociocultural similarity, chances that effective coping assistance will be offered (and accepted) should be even further increased (Thoits, 1986). On the other hand, dissimilarity in social background and life experience (and thus lower empathy) should result in ineffective, if not damaging, attempts at coping and aid.

Investigation of self-help groups by Stewart and her colleagues (Stewart, 2000) revealed that the participants valued peers for both emotional support and for their knowledge based on first-hand experience (affirmational support). This underscores the importance of social comparison theory, especially for the present study. It will be therefore important to look into how participants appraise support from professionals and other network members compared to those that have had to care for, or are caring for a person with AIDS.

### Loneliness Theory

Loneliness and isolation have been treated together in most research endeavours. Loneliness has been defined as "the subjective experience that occurs when one's existing relationships are judged to be deficient in either quantity or quality" (Peplau &



Perlman, in Rook, 1985: 246). Loneliness theorists have largely drawn on attachment theory, and argue that people seek to establish close bonds with others who can reliably provide comfort and security (Rook, 1985). Attachment theory argues that emotional attachments to others are necessary for healthy human development. Loneliness theorists have also been largely influenced by the work of Durkheim and his theory of social integration propounded in the 19th Century.

The literature on social support and that on loneliness are complementary in the way they regard the beneficial functions of social ties. While social support emphasizes the contribution to healthy functioning of help provided through social relationships, loneliness research calls attention to the value of pleasurable companionship and intimacy in enhancing mental health (Rook, 1985).

Research on loneliness puts emphasis on "...basic human needs for satisfying social ties and suggests that the absence or disruption of social bonds is in itself a cause of emotional distress" (Rook, 1985: 243). The distress suffered by lonely people is compounded by the fact that cultural stereotypes portray lonely people as losers in the market place (Gordon, 1976, in Rook, 1985). Thus, loneliness is a stigmatized condition. On the other hand "sociological analyses of social isolation suggest that social relationships serve to inhibit deviant behavior as well as to provide support and companionship" (Rook, 1985: 243).

The convergence of empirical results from these literatures is on the general proposition that "...interpersonal ties function to sustain or enhance mental and physical health" (Rook, 1985: 243). In other words, people who are lonely, socially isolated or without social support are presumed to be vulnerable to emotional and physical problems because they lack something essential that is available only through interpersonal transactions. For example, Berkman's (in Flaherty & Richman, 1989) work suggests that social isolation is associated an increased mortality risk for women. There is also other evidence from studies of humans and animals that suggests that social isolation is a major risk factor in mortality from widely varying causes (Sarason, Pierce & Sarason, 1994).

This study deals with a social phenomenon (AIDS/HIV) that has been highly stigmatized. The social stigma surrounding it is most likely to lead to avoidance by



significant others, which would in turn lead to isolation and loneliness. For instance, an intervention study by Stewart and colleagues (Stewart, 2000: 95) found that "[p]ersons with haemophilia and AIDS and their family caregivers experienced isolation and avoidance by friends who were formerly supportive." The Ministry of Health & Child Welfare of Zimbabwe has also acknowledged that people with HIV/AIDS often feel lonely, and it encourages people to help reduce this loneliness by being there and being supportive (National AIDS Coordination Program & Ministry of Health & Child Welfare, 1994). The theory of loneliness and isolation will therefore play an important part in the study, as we would want to find out whether the social networks of caregivers have changed in size since they began to care for a PWHA.

## **Social Networks**

A social network refers to a person-centred web of social relationships, and provision of social support is one of the important functions of social relationships (Heaney & Israel, 1997). In fact, according to Flaherty & Richman (1989: 1221), "...social support has become one type of social exchange between network members." And the informal social network has long been regarded as a source of helping relationships (Antonucci & Depner, 1982). A social network is thus a structure that characterizes a set of relationships (Kadushin, 1996).

More specifically, a network is:

A specific set of linkages among a defined set of persons, with the additional property that the characteristics of these linkages as a whole be used to interpret the social behaviour of the person involved (Mitchell, 1979: 2)

Marsella & Snyder (1981, in Procidano & Heller, 1983) argued for the assessment of social networks in terms of structural and functional dimensions, and Wilcox & Birkel (1983) posit structural and interactional dimensions. However, according to Israel (1982: 66), social networks can be categorised into three dimensions. Structural characteristics refer to the links in the overall network. Interactional characteristics refer to the nature of the relationships themselves or, according to Wilcox & Birkel (1983), tap the nature of the relationships, while functional characteristics refer to the functions provided by the



network, such as the provision of information, comfort, emotional support and material aid (Israel, 1982; Procidano & Heller, 1983).

Network size, density, reciprocity, gender composition, homogeneity and durability are structural properties of a social network (Israel, 1982; Procidano & Heller, 1983, Wilcox & Birkel, 1983). Distinct from social network and integration, relational content is the function and nature of social relationships with various sources such as a spouse, supervisor, friends, or relatives (Kadushin, 1996). It includes supportive interactions, which are considered as health promoting or stress-buffering. However, it is the quality of interactions (e.g., emotional intensity, mutual sharing) rather than the quantity (e.g., size and frequency) that is significantly related to well-being.

Supportive interactions work to provide instrumental support (e.g. assisting with a problem), tangible support (e.g. donating goods), and informational support (e.g. giving advice), and emotional support (e.g. giving reassurance). Social networks and social support can therefore both influence help seeking from formal and informal sources and attributions regarding causes and solutions for stressors, thereby influencing the coping process (Wills, 1985; Stewart, 1989, p.1277; Heaney & Israel, 1997). Most importantly, however, is the fact that effects of social networks include their relationship to physical and mental health, the use of services, compliance with regimens, promoting recovery, and coping with serious physical illness and injury (Israel, 1982). Research has also revealed a positive relationship between interactions with several network members and the quality of marital and working life, and ultimately general well-being (Hirsch, Engel-Levy, Dubois & Hardesty, 1990). Hence, like social support, social networks are a psychosocial factor that is related to physical and psychological well-being. For this study, therefore, it would be beneficial to map out the social networks of family caregivers that are both supportive and non-supportive.

### Social Networks and Social Support in an African Context

Radcliffe-Brown (1987) urges for a thorough knowledge of the system of kinship and marriage in order to understand any aspect of the social life of African people, economic, political, or religious. A good knowledge of these two social institutions (i.e., kinship and marriage) enables us to understand issues of social networks and social



support in an African context. According to Radcliffe-Brown (1987: 3), "a system of kinship and marriage can be looked at as an arrangement which enables persons to live together and co-operate with one another in an orderly social life", largely because of the norms, usages, and patterns of behaviour between kindred. It links people together by convergence of interest and sentiment.

The kinship system becomes part of a social structure because it consists of actual social relations of person to person as exhibited in their interactions and their behaviour in respect of one another (Radcliffe-Brown, 1987). The rights and duties of relatives to one another are part of the system and so are the terms used in addressing or referring to relatives. In short, the significance of kinship depends on the extent to which it provides a basis for social relationships (Mair, 1969), and it is within social relationships that social interactions that provide support are rooted.

The structure and function of social networks and social support are inevitably rooted in cultural context. The culture of a people "...can influence people's beliefs, attitudes, expectations, and behaviours" and "therefore provides the contextual grounding for social support to be given and received" (Dilworth-Anderson & Marshall, 1996: 68). According to Sarason, Pierce & Sarason (1990: 116), "cultural expectations ...dictate the appropriateness of different types of support from different types of relationships." The family from which we get family caregivers as well as members of the social network exists at a particular point in the history of its culture. It is the culture then that "...establishes values, resources, and behavioural rules respecting social relationships both within and without the family for age—and sex-related role behaviors and for the perception and response to illness" (Caplow et al., in Leventhal et al., 1985: 109). It is also culture that shapes kinship systems, which in turn shapes the number of kin that make up some, if not most of our significant others, or members of our social networks.

On the African continent the kinship systems historically defined the size of one's family, and many African societies have had extended family systems whereby persons live and work together. An extended family implies that a member has more relationships and more obligations to kinfolk. Hence historically, "...cooperation in tilling the fields and herding cattle [has been]...provided by a group of people bound by the obligations of kinship and marriage" (Mair, 1969). According to Mair (1969: 19),



this mutual dependence "...was a strong sanction for the performance of mutual obligations..." In pre-colonial African societies, most production, both agricultural and of consumption goods took place within the household (Dennis, 1988). Therefore, labour was "obtained through the operation of kinship obligations, particularly of the obligation of wives to work for their husbands and of the sons and daughters to work for their fathers or older male relatives before marriage" (Deere, 1979, in Dennis, 1988: 126).

In this regard, some scholars have associated the impending introduction of the money economy (and the attendant rural-urban migration) with the breaking up of the close interdependence of family members (Mair, 1969; Gutkind, 1963), or a "less ritualized and more consensual character of the bonds which tie the various kinship and political groups into an active unit" (Gutkind, 1963: 151). Although it is generally regarded as a duty for grown-up children to contribute to the support of their parents, urbanization and urbanism and its alleged attendant individualization, social distance and impersonality are purported to mean 'parents can no longer count on such help' (Mair, 1969; Gutkind, 1963). From a fairly recent study in Zambia, Skjonsberg (1989) concluded that to assume that those that have migrated into towns support their rural relatives with money or goods is a fallacy.

However, it is argued that these assertions have their roots in sociological studies of Western culture (Gutkind, 1963). Mair (1969:152) therefore concludes that "the African today depends for his material needs at least as much as sources of income outside the village as on the cooperation of his family and kinsmen..." Reporting from Congo more than four decades ago, Comhaire (in Gutkind, 1963: 169) said, "[the] extended family ties remain significant in social life ...and that the extended family remains a necessary institution for security and for educational and religious purposes." Reporting on the scenario in rural areas, however, Skjonsberg (1989: 124) is more positive, concluding that here, where an individual is not considered a liability, "...family members are there to help and support each other, even when the nature of the relationship is not entirely clear."

This argument was put forward about two decades after Colson (1971) recorded similar positive impressions about the Gwembe Tonga, also of Zambia. She observed kinship as less subject to the erosion of other interests or conflicting interests than other



relationships. She studied the Gwembe Tonga during the social upheaval of resettlement when the Kariba dam was under construction and she posits that, "in times of disaster, people will intensify their interactions with kinsmen for purposes of *emotional and substantive support*" (Colson, 1971: 70, my own emphasis). The Tonga "drew upon [kinship] for the sense of mutual responsibility which allowed them to organize for the building and maintenance of new homesteads..." (Colson, 1971: 71). According to Colson (1971: 76), the Gwembe Tonga were "...concerned...with the continuity of particular lineages and links with particular kinsmen because these are assumed to require the carrying out of reciprocal services to keep them alive" (own emphasis).

Bauer (1977) has also made similar insightful comments about the Tigray society in Ethiopia. He points out "neighbours have reciprocal rights and duties in supporting one another's life crisis ceremonies, for women the neighbourhood is the main area in which day-to-day interaction, involving help and borrowing, takes place" (Bauer, 1977: 32). With some variations, what these authors have reported about some of these African societies pertains to the Zimbabwean people. Mararike (1999: 156), for example, states that "[t]he principles of the Shona way of life revolve around kinship relations where group members are expected to love one another and share within the extended family, group or kin." He further intones that the Shona way of life is less materialistic and individualistic than that of Western Capitalist Societies. It is pertinent, therefore, in this study, to find out if kinship relations/connections come to the fore as Zimbabwean families grapple with the AIDS crises at a time when the effects of ESAP are reverberating in every socio-economic sphere.

Dilworth-Anderson & Marshall (1996) contend that the advancement of knowledge in the area of social support requires the use of more culturally sensitive conceptual and theoretical views, diverse sampling strategies, and culturally sensitive instruments. They further argue that this will diminish the use of inappropriate and irrelevant norms or reference points. It is in the same vein that Mushonga (1998) calls for culturally sensitive strategies to deal with social support for PWHA and their caregivers in rural Zimbabwe.

Hernandez et al. (1998) conducted a study in Mexico, looking into a socially marginalized urban community of Ciudad Netzahualcoyotl and the homosexual



community of Mexico City. Although both communities were marginalized, solidarity in the gay community arose from friendship, while in Ciudad Netzahualcoyotl social support derived from a local culture of kinship (Hernandez et al., 1998). On the other hand, Kanji & Jazdowska (1993) found in their study in urban Zimbabwe that the networks of friends and neighbours with whom to share goods and services are not highly developed as they are in many Latin American cities. Instead, they found the urban-rural kinship network to counter the development of a completely urban identity. This, they argue, influenced the cohesiveness of organizing activities aimed at resistance and change in the wake of economic hardship brought about by the economic structural adjustment programme (ESAP).

In Uganda, Okongo et al. (1992) found extended families to be willing to assist during funerals after someone died of AIDS. However, poverty among extended kin limited their support during illness with HIV/AIDS. The authors therefore call into question the assumption that the extended family in this particular culture provides adequate support for AIDS patients.

### **HIV/AIDS Prevalence**

Since the discovery of HIV by the Centers for Disease Control (CDC) in 1981 (CDC, 1981),<sup>1</sup> AIDS has become a global health problem (Brewington, 1994), with a near 100% fatality rate (Satcher, 1996). In the United States alone the death toll from HIV/AIDS by 1996 was well over 300 000 (Fishbein and Guinan, 1996), while over a million were believed to be infected with HIV (Fishbein and Guinan, 1996; Satcher, 1996).

AIDS has engulfed many of the world's developing countries at an ever-escalating pace. Four million people were newly infected with HIV in sub-Saharan Africa in 1997 alone (Women's International Network News [WINN], 1998). By 1999, Africa as a whole had 91% of the world's AIDS related deaths (WINN, 1999).

While bed occupancy rates were high in two major hospitals in the capital city, in Mvurwi (one of the rural areas of Zimbabwe) and the surrounding commercial farming areas hard hit by HIV/AIDS, about 80% of outpatient visits at the local hospital were found to exhibit clinical symptoms of the syndrome in September 2000 (The [Zimbabwe]



Herald, September, 25, 2000:1). The United Nations Population Fund puts the HIV infection rate in Zimbabwe at 25.84 % of the population (, which places it among the highest HIV prevalence in the world, comparable only to neighbouring Botswana (The [Zimbabwe] Herald, Monday September 25, 2000, p. 8). The World Health Organisation is also reported to estimate that between 30 and 35 % of pregnant women who visit hospitals for antenatal care in Zimbabwe carry the AIDS virus (The [Zimbabwe] Herald, Monday September 25, 2000, p. 8).

Zimbabwe once had a health system that was the envy of Southern Africa (WINN, 1998). But, fuelled by AIDS, poverty and economic instability, illness has begun to overcome the country (WINN, 1998). For example, while 100 people died of malaria in 1989, the figure was 2 800 in 1997 and, reported tuberculosis cases have risen from 5 000/year in 1986 to 35 000 in 1997 (WINN, 1998). Life expectancy, often considered to be the most reliable barometer of a nation's health, which was 61 in 1993, is expected to fall to 49 by the end of this century (WINN, 1998; Key, 1998).

The costs of treating persons with HIV infection are staggering (Holtgrave et al., 1995) and, we still neither have a cure nor a vaccine for this disease (Nunes et al., 1995). The fast-increasing number of AIDS cases is beginning to put a strain on health and social service systems. The enormity of the problem has led some commentators to call it not just a development issue, but also the foremost issue of the present and foreseeable future for many countries (Baylies, 1999).

Many scholars have called for community-based economic and psychosocial programmes to support the growing number of PWHA and orphans who are being cared for by extended families under difficult financial circumstances in Third World countries. The problem of AIDS' orphans has been noted in New York (Levine, 1992; Michaels et al., 1992); Brazil (Rolon et al., 1996); East Africa [Tanzania & Uganda] (Kidza et al., 1996; Rutayuga, 1992); Tanzania (Nkya et al., 1996); Uganda (Salaamu, 1996; Tumwebaze et al., 1992). In Zimbabwe, this issue has been addressed by Saurombe, et al. (1996) and Siwela & Germann (1996). For example, Saurombe and colleagues (1996) studied a community in which 14.7% of the children under 15 years were orphans, being cared for by grandparents, 33% of them being over 60 years. According to Rutayuga's (1992) estimate, there will be 16 million children orphaned by AIDS in 2015. And by



1999 it was claimed 95% of all AIDS orphans were African. However, Baylies (1999) argues that an emphasis on community responses and community responsibility for PWHA in Africa, though consistent with participatory initiatives, there is danger in this strategy becoming the poor man's and poor woman's lot. With this approach, she argues, communities would be left to 'help themselves' because of the sheer enormity of the problem and the lack of resources to deal with it.

### **The Position of Women, AIDS, and Social Support**

Gender is one of the bases on which society is stratified (Thorogood, 1992; Hannay, 1992; Das Gupta, 1995; Vatuk, 1995), with low status often attributed to women (Crook, 1994). This has negative consequences for the health of women (Trypuc, 1988; Thorogood, 1992); hence gender is regarded as a major determinant of health (Coburn et al., 1998; Labonte, 1994; Labonte and Penfold, in O'Neil and Pederson, 1994; Clarke, 1990). Since poor health has negative consequences on development and vice-versa, "gender, health and development make up a dynamic triad" (Ostergaard, 1992: 110). Literature abounds with evidence pointing at health inequalities on the basis of gender the world over (Doyal, 1995; Ostergaard, 1992; WHO, 1992; Cook, 1994; Smyke, 1991).

There is work suggesting that social isolation is associated with an increased mortality risk for women (Flaherty & Richman, 1989). This is of importance to us because HIV/AIDS has been linked with stigmatization and discrimination, leading to isolation and loneliness (Mutetwa, 2000; Stewart, Hart & Mann, 2000; Stewart, 2000; The Herald [Zimbabwe], May 18, 2000; Thompson, 1999; Kalondo, 1996; Hwayire, Sibanda & Phiri, 1996; Anderson, 1994; Cassidy, 1990; Kadushin, 1996; Bourgon & Renaud, 1990; Gordon-Garofalo, 1998; Duarte, Palma & Gomez, 1998).

There is extensive empirical evidence linking gender and social support (cf. Turner & Marino, 1994; Hirsch et al., 1990; Flaherty & Richman, 1989; Antonucci, 1982, 1985). Research has found strong gender differences in both the elicitation and provision of social support (Flaherty & Richman, 1989). These gender differences are based on gender specific socialization experiences, which are perpetuated within adult social roles. This argument is based on research by Hoffman (1977) and Eisenback & Lennon (1983) that has shown female children to be more empathic, with the quality



becoming more prominent in adulthood in situations where gender role expectations encourage women to display appropriate social concern (in Flaherty & Richman, 1989: 1221, Hirsch et al, 1990).

According to Antonucci (1982, 1985) and Flaherty & Richman (1989: 1223) women either receive or utilize more support than men, and, it is their "dependency needs [that] serve as a driving force in the solicitation of supporting relationships for women" (Flaherty & Richman (1989: 1226). They are also reported to have more extensive and more varied networks from which they draw support than men (Antonucci, 1982, 1985). Skjonsberg (1989: 140) studied the Kefa community in Zambia and also found "women [to] have a wider network of friends than ...their husbands, people with whom they cooperate and who will support them in times of need". However, a review of available evidence by Vaux (1988, in Turner & Marino, 1994) has concluded that empirical findings regarding gender differences in social support are mixed and inconsistent. Therefore, "while women appear to be advantaged in terms of confidants and ...certain other support resources, many studies that have considered this issue have reported little or no difference by sex in level of perceived social support" (Turner & Marino, 1994: 197). Turner and Marino's (1994) study revealed that men reported the availability of more friends, while women indicated significantly higher levels of contact with both friends and relatives. According to the authors, "one basis for the higher levels of social support experienced by women may be the higher levels of contact they routinely have with both family and friends" (Turner & Marino, 1994: 204).

Hirsch et al. (1990) argue that support for nonwork identities are important for women. One of the reasons is the early socialization that prepares them for expressive roles emphasizing emotional nurturance and support. General emotional support is therefore necessary in order not to become burned out from the expressive role, especially for those engaged in caregiving roles (Hirsch et al., 1990). The second reason is that women are particularly vulnerable to interrole conflict between family and work, as well as overload from both sets of responsibilities (Hirsch et al., 1990). For this study, therefore, it is pertinent to map out the different supports women are getting, distinguishing general support, support for their caregiving responsibilities, as well as support for the other household roles.



The social roles, social position and lifestyles of men and women are not rooted in physiological sex differences but are socially constructed within a particular culture (Morgan et al., 1985). Roles identified with female gender (feminine roles) are usually not valued in social and economic terms (Cook, 1994); hence women occupy more or less “subordinate positions in most social and cultural contacts” (Doyal, 1995: 7). This phenomenon is what Doyal (1995) calls ‘culture devaluation’, which manifests itself in many ways. One of the ways is the devaluation of caregiving roles, which are predominantly performed by women.

In the Third World more than three quarters of the population live in rural areas and are poor (Lean, 1995; Brara, 1983) and, poverty is known to increase the risks of sickness as well as make it difficult for people to respond to health promotion advice (Jones, 1997). A large percentage of these rural dwellers are women and children, because labour migration works in favour of men. In addition, the majority of rural people do not have a stable source of income, and have no stable social security (Gsanger, 1994). Most women in the Third World are employed in the agricultural sector, where the work is strenuous, and they encounter dangerous pesticides (Doyal, 1995; Dennis, 1988; Robertson, 1988). Rural women also face heavier workloads (fetching water, and agricultural activities) and have more health problems, like the urban poor (Cook, 1995; Batezate and Mwalo, 1989; Klouda, 1983). These conditions pertain to Zimbabwe as well.

In a study done in Zimbabwe, AIDS was reported to be prevalent among women with low economic status (Hwayire, Sibanda & Phiri, 1996). Poverty has been reported to drive young women into prostitution simply to buy food for children or to survive in Zimbabwe (Bassett & Mhloyi, 1994; Anderson, 1998). Hence Baylies’ (1999) argument that the high levels of vulnerability to AIDS in Africa cannot be separated from broader afflictions of poverty, indebtedness, social and economic disruption. Because of lack of formal employment opportunities, many women have responded by working longer hours in the informal sector with decreased real returns (Mupedziswa & Gumbo, 1998; Kanji & Jasdowska, 1993). Such a scenario further sinks women into marginalisation. To try and stay on top of things, women in the informal sector find themselves increasingly



participating in social support groups, particularly church groups (Mupedziswa and Gumbo, 1998: 90; Kanji & Jasdowska, 1993).

According to Kanji & Jasdowska (1993) the traditional class and gender inequalities that existed in Zimbabwe are being exacerbated by the economic structural adjustment programme (ESAP), a strategy to development that serves the interests of international and national capital, introduced by the government of Zimbabwe in 1991. In all the other countries where it was introduced, there has been a combination of rising prices, lower real incomes, and restricted government spending in the social sectors tends to lead to an alarming deterioration in living conditions of the poor majority of these countries (Kanji & Jasdowska, 1993). This means that the poor tend to get poorer (Ostergaard, 1992).

In their study conducted in one of the suburbs in the Zimbabwean capital, Harare, Kanji & Jasdowska (1993) found women to be more adversely affected by ESAP than men. According to Kanji & Jasdowska (1993), price rises in food and basic goods and cut backs in social services affect women more because of their primary involvement in household consumption and welfare. From their findings, they conclude that there is a visible process of impoverishment taking place in this suburb, with decreasing food consumption, more intensive work by women with diminishing returns, and diminishing savings and more anxiety about the future. In women-headed households, access to income and resources tends to be lower, and the effects of ESAP are argued to be severe (Kanji & Jasdowska, 1993). To link back to the argument made by Basset and Mhloyi (1994), it these impoverished conditions that lead women to engage in prostitution in order to support themselves and their families. It is in that process that the powerless women become high risk for HIV infection.

In most parts of Africa, greater economic dependence of a woman makes her more powerless. This quotation is more telling:

*The women tell us they see their husbands with wives of men who have died of AIDS. And they ask 'what can we do? If we say no, they'll say pack and go. But if we do where do we go to?'... (Ugandan MP M. Matembe, in Doyal, 1995: 78).*

In Zambia, for example, women were noted to be disadvantaged when it comes to STDs and AIDS, because they do not have the power to negotiate whether to have protected sex



with a husband with multiple sexual relationships with other women (Key, 1995), a phenomenon also noted by Basset and Mhloyi (1994) in Zimbabwe. Under these circumstances there is little positive mental and physical health for women.

As noted earlier, much of the caregiving for discharged AIDS patients in Zimbabwe falls on women (Mushonga, 1998), either as mothers or spouses. The same situation has been observed in Uganda, where the process of caring for PWHA was observed to be stressful (Sharpe et al., 1994; Kaleeba et al., 1994). In North America women also outnumber men as family caregivers, and they experience strain, high role demand, and sometimes depression (Neufeld & Harrison, 2000).

For rural women, however, who are arguably in a poorer state of health, who spend most of their time caring for children and performing arduous agricultural activities for a living, care-giving for family members with AIDS becomes an additional burden. Again, the general poverty in the communities worsens the “victims” and caregivers’ socio-economic status. The majority of rural families who are low and no income families have no margin to absorb the costs of HIV illness, resulting in increased social inequity along rural-urban (class) and gender lines. Poor health from work overload (including caregiving duties) and powerlessness hinder women’s full participation in the socio-economic environment. This reinforces their subordinate position in the community, further reducing their support resources, and this completes the cycle.

Given this scenario, it is pertinent to explore the social relationships of these caregivers, as well as assess their support needs fulfilment amidst the tightening economic situation and the escalating AIDS cases they are continuously called upon to take care of. Hence it is important to factor in a gender perspective into the study since patriarchal structures continue to dictate women’s roles (within households), to the detriment of their general well-being/quality of life.

## **HIV/AIDS and Societal Reaction**

PWHA and their caregivers are part of society. Society reacts in different ways to new social phenomena, sometimes favourably, and sometimes unfavourably if the phenomena is felt to be life threatening. Sometimes society acts this way because there is



not enough knowledge about that particular issue. AIDS is one such phenomenon that has provoked a negative societal reaction since it was discovered in the early 80s.

### Stigma and Isolation

Stewart (1989: 1279) has posited that: "...caretakers of the chronically ill and the visibly disabled tend to be socially isolated and can suffer from a mismatch between the individual and the environment." AIDS is a chronic disease and caregivers of PWHA presumably also suffer from this mismatch. Due to the social stigma attached to AIDS, caregivers would inevitably get ostracised, become lonely and, loneliness would impact on physical well-being and psychological health (Stewart, 1989). In the Third World, where AIDS is regarded more as a scourge than a chronic disease, the stigmatization and its effects must be quite staggering. For example, while trying to paint a scenario of AIDS prevalence as well as encourage concerted preventive efforts in the paper's comment section, the editor of The [Zimbabwe] Herald (Monday, September 25, 2000, p. 8) unfortunately talks of 'the seriousness of the scourge'. Such media reporting only delay the onset of a mindset and environment in which AIDS can start to be regarded as a chronic disease.

People with AIDS live in communities full of prejudice and social stigma surrounding HIV/AIDS (Mutetwa, 2000; Stewart, Hart & Mann, 2000; Stewart, 2000; The Herald [Zimbabwe], May 18, 2000; Thompson, 1999; Kalondo, 1996; Hwayire, Sibanda & Phiri, 1996; Anderson, 1994; Cassidy, 1990; Kadushin, 1996; Bourgon & Renaud, 1990; Gordon-Garofalo, 1998; Duarte, Palma & Gomez, 1998). According to all these authors, these stigmatisms cause many psychosocial problems for PWHA, and they equally affect caregivers of PWHA. Hence, PWHA may be affected more by social reactions than by the disease itself (Kalondo, 1996).

This phenomenon is widespread in Africa (Anderson, 1994; Kolondo, 1996), Zimbabwe included (The Herald [Zimbabwe], May 18, 2000; Mutetwa, 2000; Hwayire, Sibanda & Phiri, 1996). For example, 20 co-ordinators of AIDS service organisations and networks of PWHA from 10 different Southern African countries that attended a training course (in Harare) on how to work with other partners in the fight against the disease mid May, 2000 voiced their concern over the church's judgemental attitude and



the media's stereotypical portrayal of infected people (The [Zimbabwe] Herald, May 18, 2000). For example, according to these participants the continued use of derogatory terms like 'victims' and 'sufferers' by the media discriminates as well as disempowers PWHA. They also felt that the church's perspective was that those infected with the virus deserved to be punished for 'loose morals'. There are also some in society who go along with this view, and believe that "AIDS is divine retribution for immoral lifestyles" (Mutetwa, 2000: 1).

The Zimbabwe Ministry of Health & Child Welfare (1996) contends that a lot more work needs to be done to effectively address the issue of discrimination. Among relatives, for example, "sometimes when a husband knows his wife has HIV or AIDS, he sends her away from home [and] sometimes it is the wife who abandons the husband with HIV or AIDS" (National AIDS Coordination Program & Ministry of Health and Child Welfare, 1994: 34). Apart from church leaders and relatives, friends, professionals (such as doctors) and co-workers have also been reported to cut contacts with people who have been diagnosed with HIV/AIDS (Mutetwa, 2000). Stewart, Hart & Mann (2000) report finding this type of prejudice and insensitivity from health professionals and friends among persons with hemophilia and AIDS in Canada.

These social stigmas lead to social isolation and loneliness for PWHA and their carers (Stewart, Hart & Mann, 2000; Mutetwa, 2000; Casaux & Reboreda, 1998, Hwayire et al., 1996). Hence carers of PWHA are also 'co-infected' (Adams & de Castro, 1992) because they undergo the same stresses and isolation (Mutetwa, 2000). [They might also be really infected with HIV, and this becomes a double burden.] Isolation, in turn, is argued to lead to emotional and physical health problems (Rook, 1985). According to Mutetwa (2000), this stigmatisation and discrimination leads to many people who are HIV positive opting to 'hide their diagnosis because they fear isolation, persecution, ...and rejection'. It is pertinent therefore, in this study to find out the caregivers' perceptions of the effect of an HIV diagnosis on their social network, including the flow of resources from network members and other exchange processes.



## **Social Support for People with HIV/AIDS and Caregivers**

PWHA experience a number of crises and a wide range of situations that make them need social support (Dupras et al., 1990; Kadushin, 1996). First of all, there are stereotypes and social stigma associated with AIDS (Cassidy, 1990; Kadushin, 1996; Bourgon & Renaud, 1990). Because of the disease and the stigmatization related to it, PWHA confront many stresses, such as isolation, anger, loss of status and roles, loss of hope, fear of loss of job, friends and lack of financial resources, disfigurement, fear of imminent death, and the need to change patterns of physical intimacy (cf. Stewart, Hart & Mann, 2000; Stewart, 2000; Mutetwa, 2000; Gordon-Garofalo, 1998; de Mattos & Mendonca, 1998; Kadushin, 1996; Adams & Decastro, 1992; Dupras et al., 1990; Paguin, 1990).

The import of this is that these factors place PWHA at high risk of psychological problems such as depression, anxiety, and suicidal ideation (Kadushin, 1996). An individual facing acute or situational stressors will most often have an increase in psychological and psychosocial needs (Stewart, 1989). It is argued that caregivers of PWHA also go through the same psychosocial problems, and also have the same psychological and psychosocial needs (Mutetwa, 2000). This is sound basis for arguing for social support provision for caregivers of PWHA.

AIDS is also a progressively debilitating disease in which the PWHA requires a diverse range and, often, intensive set of formal and informal services (Katoff, 1992). People with chronic diseases like cancer, and Alzheimer's have been noted to need a tremendous amount of social support (Bulkwater, 1991; Bloom, 1996; Pennix et al., 1996). AIDS has emerged from being a plague to acquire a chronic disease status (Beaudin & Chambre, 1996; Uribe et al., 1994; McDonald, 1990), and the need for social support is tremendous.

### Research

Several studies have noted an association between social support and more active coping by PWHA (e.g., Mayne & O'Leary, 1993; Barosso, 1997; Friedland et al., 1996). First of all, social support has been found to increase the quality of life of PWHA (Nunes et al. 1995; Friedland et al, 1996). In a study by Friedland and colleagues (1996) in



Toronto, they found income and social support to be positively related to quality of life. Quality of life was also observed to improve in PWHA with increased social support in Kenya (Aduwa, Lenya & Kowi, 1998), Venezuela (Bastardo & Kimberlin, 1998) and United States (Singh et al., 1998). In a study conducted in Quebec, PWHA revealed having experienced more stress because of an absence of support or simply negative support, than because of physical deterioration caused by the disease (Hart, Mann & Stewart, 1992). This is because social support buffers the negative effects of stress on health (Jankowski et al., 1996).

According to Kadushin (1996), more studies have been done with gay men, and social support has been established as an important resource in gay men's ability to cope with AIDS in most of these studies. Networks have been found to offer more valuable social support to PWHA. In a study by Barosso (1997), participants developed networks that helped them to deal with AIDS, with affect and affirmation having a significant effect on ambiguity among participants. In a recent five-year study on HIV infected men, researchers have found that passage to AIDS status was greatly accelerated by stressful events and by low levels of social support (Key, 1999).

Social support has also been associated with elevated CD4 cell counts (cf. Kadushin, 1996; Hedge, 1991). Therefore, it is clear that social support systems are one of the most important resources for practical and emotional support for PWHA. The various psychological and psychosocial stresses that PWHA go through, and the promise of social support shown above in bringing about better quality of life create an urgent need for well-coordinated medical and psychosocial interventions (Berthelot, 1990; Sikkema & Kelly, 1996).

So far we have noted studies that provide empirical evidence that attests to an association between social support and more active coping by people PWHA (Bastardo & Kimberlin, 1998; Barosso, 1997; Friedland et al., 1996; Mayne & O'Leary, 1993), and social support and quality of life (Singh et al., 1998). By implication, social support should also facilitate coping with the stress associated with caring responsibilities, alleviate social isolation and promote or enhance the health of caregivers.

The majority of studies done in developed countries have underscored the need for informational, instrumental and emotional support for family caregivers of HIV/AIDS



patients to improve coping mechanisms, decrease stress, and thereby improve their quality of life (Catalan, Meadows & Le Marechal, 1999; Turner, Pearlin & Mullan, 1998; Clark-Alexander & Rose, 1998; Eadie, Raymond, Yates & McEwan, 1992). The study by Turner et al., (1998) underscores the importance of network factors (such as frequency of contact, conflict, and community integration) to caregivers' perceptions of emotional support. They also found that the level of informal instrumental support the caregiver receives depends largely on the factors that place greater demands and time constraints on caregivers, such as being employed and caring for an AIDS patient with greater functional limitations (Turner, Pearlin & Mullan, 1998).

Some of these studies from developed countries have highlighted how poverty limits family caregivers' ability to perform caregiving duties and limits their likelihood of asking for support (Trubey, Williams & Berrien, 1997; Vera, Goldman & Bressler, 1997). Poverty has also been singled out as an important factor in coping with caregiving responsibilities (for both family caregivers and communities in general) in the few studies done in the developing nations in general (Baylies, 1999), Uganda (Okongo, Seeley, Kajura, Mulder & Wagner, 1992), and Zimbabwe (Mushonga, 1998; Woelk et al., 1997; [Zimbabwe] Ministry of Health and Child Welfare, 1996). Mushonga (1998) argues for the need for stronger efforts to provide informational support to PWHA and their caregivers in Zimbabwe.

In a recent study done by Woelk and associates (1997) in Zimbabwe, the majority of caregivers for AIDS patients were found to be women. More than half of the 52 caregivers who received help with patient care got it from close relatives, mostly siblings and parents. Due to the level of poverty among the households affected by HIV/AIDS, the caregivers expressed the need for instrumental support, above anything else. More than half (30) of the caregivers did not receive any help with food for the patient from close or distant relatives. However, this study only had a peripheral focus on social support for caregivers, and the major focus was on the assessment of the formal home-based care program.



In a bid to fill the void created by sparse investigations into the impact of interventions designed to enhance social support available to parents of children with chronic conditions, Ritchie et al.(2000) conducted an intervention study that tested the impact of a twelve-week telephone support intervention for parents (n = 103 mothers & n = 11 fathers) of children with diabetes, cystic fibrosis, or spina bifida, in a randomised control trial. The intervention, in the form of support groups, came on the heels of an assessment study that examined the caregiving demands and related social support that mothers experience in caring for these children.

The intervention therefore offered "...varied types of social support from peers in relation to specific types of caregiving demands and to enable the social support processes of social learning, social comparison, and social exchange" (Ritche et al., 2000: 69). The authors posit that the "intervention study provides ...evidence of the needs of this population for more support than is currently available" (Ritchie et al., 2000: 80). While they argue that most studies do rarely test the impact of interventions on health, their important finding was that, "the participants reported increased social support, enhanced coping, increased confidence, and changes in perspectives and in their behaviours in health care encounters" (Ritchie et al., 2000: 57). Although this intervention does not involve patients with HIV/AIDS, it is pertinent to our study because in the West AIDS is now regarded as a chronic condition/disease. Also, what is important is the fact that the study involves family caregivers, which is the central focus of our study.

An intervention study much more pertinent to the issues of my study is that conducted by Stewart, Hart & Mann (2000), with 30 HIV-infected hemophiliacs, 23 family caregivers, and 17 bereaved family caregivers. This intervention study made use of both qualitative and quantitative data to illuminate the experiences of PWHA and their family caregivers and their need of support from both peers and professionals. The intervention consisted of telephone support groups co-led by a professional and a peer, and provided emotional, informational, and affirmational support. The "study revealed that participants experienced loneliness because of prejudice, insensitivity, avoidance,



and isolation behaviours by family, friends, and professionals" (Stewart, Hart & Mann, 2000: 115). The authors report that there were significant positive changes in support satisfaction and support needs. More importantly, however, "caregivers reported enhanced confidence and coping and diminished loneliness and isolation, and affected men described changes in coping behaviours and reduced emotional isolation" (Stewart, Hart & Mann, 2000).

A number of intervention studies have been carried out in South American countries that bolster the argument for providing caregivers of PWHA with different kinds of support (de Mattos & Mendonca, 1998; Duarte, et al., 1998; Casaux & Reboreda, 1998; Uribe et al., 1994). Out of these interventions, only the Argentinian one (Casaux & Reboreda, 1998) specifically mentions improving the quality of life of both PWHA and their caregivers.

The support groups created for parents of HIV+ children in Brazil were meant to provide emotional support to the caregivers (de Mattos & Mendonca, 1998). The groups enabled the parents a space to share their anxieties, dreams, fears of death and discrimination, difficulties relating to the child, and difficulties coming to terms with the diagnosis. Most importantly, the parents developed a strong solidarity and companionship with each other, finding support and learning creative ways of dealing with challenges, lack of resources and hospital adversities.

The study intervention reported by Casaux & Reboreda (1998) was based on findings that HIV+ patients and their caregivers are faced with isolation, which impacts negatively on their on their ability to gather resources. The intervention is also based on support groups through which caregivers shared their experiences (such as anxiety, sorrow, fear, anger and doubts). On the other hand support groups for PWHA were designed to enable self-empowerment. Some of the major achievements are: better support for critical moments, better use of medical and community resources, reinforced esteem, and empowerment of the PWHA, caregivers and the social network. According to Casaux & Reboreda (1998), as empowerment between the patient and significant others reaches an optimum point, their life standard changes for the better.

Apart from offering treatment and care, THs can be an important source of information for HIV/AIDS prevention. They also provide, through counselling, critical



emotional support for their clients and community members affected by HIV. It is gratifying to note that others have already taken the initiative to work with THs so that they can provide different types of supports to their clients. In Zimbabwe, efforts have already been made to conduct 23 workshops to train an average of 30 THS/workshop to perform these functions (Willms et al., 1995).

### Outstanding Research Issues

The dearth of literature on social support from the developing countries, particularly Africa, makes it imperative that in-depth knowledge about how different cultures provide the contextual grounding for receipt and giving of social support be systematically collected. Although some of the research reported above has focused on support for caregivers, it has done so in an effort to alleviate the impact of stressors attendant to caregiving roles, and not as a health promotion strategy to enhance their well-being as well.

Since "health status and health behaviour depend on individual and group ability to interpret, manipulate, and cope with environmental stressors" (Stewart, 1989: 1276), a network and social support intervention aimed at caregivers of PWHA would be especially likely to empower female caregivers, who are already part of a marginalized segment (i.e. women) in Zimbabwean society. However, such an intervention is only possible after a thorough understanding of their needs.

Apart from understanding the needs of caregivers, "...more needs to be known about how support is or can be provided in an effective manner" (Sarason, Pierce & Sarason, 1994: 162). According to Sarason, Pierce & Sarason (1994), the topic of the provision of social support (how it is provided, by whom, under what circumstances) has been barely touched on. In this study, therefore, we will need to understand support provision in the everyday lives of caregivers, support geared towards caregiving responsibilities, and the various sources of support.

Moreover, although we have a substantial theoretical base in sociology suggesting that macrosocial features influence social relationships, there has not been much empirical evidence to illuminate the nature of that relationship (Turner & Marino, 1994). We also need to know how social support varies across subgroups of the



population. In this case, we need to know the effects of *culture, the wider economy, SES, gender, marital status, and age* on the social construction of AIDS, social support provision for caregivers of PWHA, and perceptions of support by these caregivers. (I believe that culture, and the social construction of AIDS that it is likely to influence, would directly influence social stigmatization and the coping strategy of withholding the diagnosis of HIV status). Such a comparative perspective would be an important step towards illuminating the impact of social structures on processes of social support. More so, we need to know the effect of rural-urban differences on support needs, social relationships and social support processes. The rural-urban dichotomy is generally regarded as one major source of disparities in wealth, resource and social services provision in Third World countries. Such a comparative approach would shed more light on the differences in social experience and/ or contemporaneous life circumstances.

Home care, in the context of community support, has been suggested as a panacea for the problem of affordability regarding expensive hospital-based services for people with HIV/AIDS among poor rural families in developing countries elsewhere (Plianpadung et al., 1996; Buono et al., 1996; Ankrah et al., 1992; Simon et al., 1992; Uribe et al., 1994; Mulenga et al., 1996; Kolondo, 1996; Okwii, 1996), as well as in Zimbabwe (Saurombe et al., 1996; Mushonga, 1998; Zanamwe et al., 1998). It is this home care that places the burden of caring on family/informal caregivers, particularly women. This shift in emphasis warrants a thorough investigation of the capacity and needs of family caregivers to fulfil this obligation. This is a gap this study hopes to fill, by way of a capacity and needs assessment through the experiences of caregivers.

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### **Endnote**

1. It was on 5 June of 1981 that the CDC, in a report on pneumocystis pneumonia to Morbidity and Mortality Weekly Report first recognized the existence of what it would later term Acquired Immune Deficiency Syndrome (AIDS) and began documenting cases.



## CHAPTER III

### METHODS

#### Overview

This cross-sectional, exploratory, and qualitative research project seeks to describe the lived experiences of informal/family caregivers of PWHA with formal and informal social support, considered one of the main psychosocial determinants of health (cf. Health Canada, 1999a; 1999b). Respondents comprise a purposive sample of urban and rural caregivers of PWHA, and research triangulation (i.e. data, theoretical, researcher & methods) was used to improve confidence in the findings. The study data were generated using a combination of observations and interviews (semi-structured and unstructured) with family caregivers of AIDS patients. Contact with family caregivers was made through organizations/institutions that offer support to PWHA, and are involved in community-based home care. Following the suggestion given by Creswell (1998), this chapter will pay detailed attention to the philosophical perspectives behind the study, as well as show a rigorous attention that was paid to procedures or steps in the process, from data gathering to analysis.

#### Rationale for Qualitative Methods

Creswell (1998: 15) defines qualitative research as:

[A] n inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem...[and t] he researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting.

Denzin & Lincoln, cited in Carlson, Siegal & Falck, (1995: 7) note that the word qualitative implies:

[A] n emphasis on process and an in-depth understanding of perceived meanings, interpretations, and behaviors, in contrast with the measurement of the quality, frequency, or even intensity of some externally defined variables.

This means qualitative research is "largely an inductive process by which a scientist attempts to gain an understanding of the *patterned meanings, perceptions, beliefs, values*,



and *behaviors* of a particular group of human beings in relation to a research problem" (Carlson et al., 1995: 18, own emphasis; Morse & Field, 1995). To achieve these aims, "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Denzin & Lincoln, in Carlson et al., 1995: 7). All the characteristics of qualitative research mentioned above make it rigorous and time consuming (Creswell, 1998).

Researchers have to make assumptions about existence and about how we come to have knowledge. A different epistemological foundation informs traditional empiricist research about the nature, origin and limits of knowledge (Hall, 1977; IHPR, 1995; Fals Borda, 1986). This positivistic or empiricist orientation makes traditional assumptions, that there is objective reality or social facts out there that are independent of who is observing them or any other structures or values (Morse and Field, 1995; Creswell, 1994; Hammersley & Atkinson, 1983). In other words, epistemological and/ or ontological priority is given to directly observable phenomena (Hammersley & Atkinson, 1983). This is a deductive approach, which works by testing theories and hypotheses (Morse and Field, 1995). 'Objective' data is, therefore collected by the use of quantitative methods (i.e., surveys and experiments) (Creswell, 1994).

On the other hand, qualitative research makes non-traditional assumptions, which state that there is no objective reality 'out there'. The only reality is that constructed by the participating members, hence the need to obtain information in respondents' own words. According to Creswell (1994: 8), "multiple realities exist in any given situation..." and, a researcher that believes in this nature of reality needs to report all the realities, a process allowed for by qualitative methods. Qualitative methods are therefore, "...used to interpret the meanings of both participants and non-participants ...and the multiple realities of each in a given situation" (Swanson & Chapman, 1994: 69).

The qualitative approach is called social *constructivism* (Creswell, 1994; Labonte, 1993), or *naturalistic* paradigm (Harris, 1992; Hammersley & Atkinson, 1983). The researcher takes a different role, instead of standing 'outside' the facts or world that one is observing, the researcher interacts with those taking part in the study. An 'insider' view allows the researcher to understand human actions, which are infused by *social*



*meanings*: intentions, motives, attitudes, and beliefs (Hammersley & Atkinson, 1983). These *meanings* are learned, or “socially constructed” (Swanson & Chapman, 1994: 69).

Because of these constructivist philosophical underpinnings, I chose to use qualitative methods to study the experiences of family caregivers of PWHA. This perspective counteracts the idea of seeing caregivers as a homogeneous class, which merely reacts to outside socio-econo-cultural forces. It is natural that caregivers would have different values and interests; hence they are regarded as a heterogeneous group. This perspective helped me understand some of the impediments to provision, receipt, as well as reciprocation of support as I focus on interpersonal relations, social network functions, and how participants and support institutions legitimate their courses of action. That is, participants were treated as active elements in the social support processes. This holistic and detailed focus also helped me make connections between micro-level (interpersonal) and macro-level processes (institutional and structural) and decisions. According to Creswell (1998), use of qualitative methods also depends on the need to present a *'detailed view'* of the topic.

This holistic view of the topic, interfacing micro and macro issues, involved looking into the issues of culture and its influence on the allocation of the caregiving role, and how it affects the social support processes; as well as gender issues. Since women are predominantly given the caregiving role, their marginalized status in the society needed to be looked at in relation to culture and caregiving responsibilities. According to Creswell (1998: 19), "a hallmark of qualitative research today is the deep involvement in issues of gender, culture, and marginalized groups", practical topics that are close to the people. These are endemic and inescapable issues within the topic at hand, and a fair understanding of the intricacies involved warranted the use of qualitative methods.

Qualitative research, therefore, looks into people's life experiences (Morse & Field, 1995), or how people live their lives and make sense of them, what Neutens & Rubinson (1997: 142) call "participant perspective". According to Creswell (1998), the choice to do a qualitative study should depend on the nature of the question. "The research question [in a qualitative study] often starts with a *how* or *what* so that initial forays into the topic describe what is going on...in contrast with quantitative questions that ask *why* ..." (Creswell, 1998: 17).



The type of questions that needed to be answered in the present study could only be answered by a qualitative study. The aim of the study was to use qualitative methods in order to obtain a rich understanding of the lived experiences of caregivers of PWHA – *how* they cope with their daily caregiving (and other) duties; *what* it is like to care for someone suffering from a highly stigmatised disease, such as AIDS. In the words of Morse & Field (1995:18), qualitative research "...opens a window into the world of others". In my case, it was aimed at providing empathetic understanding of the world of caregivers. I was a learner. Hence, apart from the nature of the fundamental questions, I also employed a qualitative approach in order "...to emphasize [my] role as an *active learner* who can tell the story from the participants' view rather than as an "expert" who passes judgment on participants" (Creswell, 1998: 18).

The exploratory nature of this study also made it pertinent that qualitative methods be used. As indicated in the previous chapter, there is paucity of literature on social support for caregivers of PWHA, particularly in developing countries. While in the field, therefore, I had to systematically explore the topic as a learner. The inductive nature of qualitative research (Morse & Field, 1995; Carlson et al., 1995) was found well suited to the exploration of, and development of knowledge on this topic.

Considering the dearth of literature on social support for caregivers of PWHA in Zimbabwe, the use of qualitative methods was also considered necessary in order to make policy recommendations and the attendant health promotion goals culturally meaningful and effective at the local level. Gathering culturally meaningful data was considered of primary importance; hence participants were not removed from their natural setting. They were interviewed in their homes in order to situate caregiving responsibilities and social support processes in context. This leads us to another important reason qualitative research was used. According to Creswell (1998: 17), one must "choose a qualitative approach in order to study individuals in their *natural setting*".

The sensitive nature of the topic, involving participants talking about HIV/AIDS (phenomena heavily stigmatised in society), also made it pertinent that I use qualitative methods. According to Carlson et al. (1995: 8), "qualitative research is often the only means available for gathering sensitive and valid data..." Lambert, Ashery & Needle



(1995) have fruitfully used, and recommend the use of qualitative methods in understanding the dynamic nature of drug abuse and HIV.

## **Theoretical Frameworks**

A number of complementary theoretical frameworks, all germane to the purposes of this study were used. Theory is a guide to practice, and, according to Fetterman (1998: 15), "no study...can be conducted without an underlying theory..." In this study I choose to call this theory 'theoretical/philosophic framework'. According to van Manen (1997: 27) this is the methodology, or "the fundamental assumptions and characteristics of a human science perspective...includ[ing] the general orientation to life, the view of knowledge..." Explained in the section above are the epistemological and ontological underpinnings of the interpretive/naturalistic inquiry (i.e., qualitative methods). However, those underpinnings have partly derived from theoretical frameworks (with great affinity), such as: phenomenology, ethnography and symbolic interactionism, which were central in guiding aspects of this study. In other words, qualitative methods are harmonious with the ethnographic, phenomenological, and symbolic interactionist approaches used in this study. These approaches treat participants as actively constructing and choosing their destinies in most cases.

### Symbolic Interactionism

Symbolic interactionism, which emphasises the importance of perceived meaning and quality of interactions on human behaviour (Israel, 1982), was used as a framework to guide data collection and analysis. This study was hoped to elucidate our understanding of the meanings of social support from a culture that is typically considered less individualistic than that of Western societies. Because of these cultural differences, there is a need for a theoretical perspective that focuses on experiences and interpretation of meanings in interactional processes of social support.

Symbolic interactionism originated with George Herbert Mead, who saw communication as the key to understanding the connection between intelligence (mind), self-consciousness (self), and the community (society) (Charon, 1998; Neutens &



Rubinson, 1997). Mead (1863-1931), who was a philosopher, was chiefly influenced (just like his predecessors) by the philosophy of *pragmatism*, the work of Charles Darwin, and *behaviorism* (Charon, 1998).<sup>1</sup> There are five central ideas to symbolic interactionism. These ideas are centered on how individuals interact with others, and with themselves in order to define what is taking place around them so that they can make decisions about how to act in each particular instance (cf. Charon, 1998).<sup>2</sup> Linking these five ideas in symbolic interactionism are three central concepts: social interaction, interaction with self, and definition of the situation (Charon, 1998).

According to Wolcott (1994), the interactionist approach recognizes the existence of multiple realities in the form of multiple goals, problems, and situations. Symbolic interactionism "...holds that the development of self is an interpretive process and occurs through discourse with one's world" (Blumer, in Swanson & Chapman, 1994: 73). The "theory [also] asserts that people's self-concepts are influenced by the way others respond to them" (Neutens & Rubinson, 1997: 144). Hence, according to Bogdan & Bikken, cited in Neutens & Rubinson (1997: 144), "people act not on the basis of predetermined responses but as interpreting, defining, symbolic animals whose behavior the researcher can only understand by entering the defining process" through the use of qualitative methods, such as participant observation. What is important is the fact that the 'defining' process is a shared event, dependant on meanings attached to the actions or interactions. According to Neutens & Rubinson (1997), the people involved in the defining process usually develop congruent definitions of interpretations. In the view of interactionists, people's actions are caused by interpretations of stimuli that are revised continually as events unfold (Hammersley & Atkinson, 1983).

What is also significant about this perspective is the way human beings are accorded the ability to shape their own destinies, contrary to other social-scientific perspectives that emphasise how passive and caused we all are. "Symbolic interactionism describes the actor as a being who thinks, defines, applies his or her past, imagines the future, and selects objects in the environment for his or her own use", posits Charon, 1998: 28). This perspective played a crucial role in how I focused on caregivers as largely and actively involved in determining some of the social support interactions surrounding their caregiving role.



## Ethnography

The study was also influenced by the ethnographic approach. Simply put, “ethnography is the term used for the description of a particular culture” (Neutens & Rubinson, 1997: 144), or “...what ethnographers actually do in the field...” (Fetterman, 1989:26). According to Carlson et al. (1995: 17), “ethnographers are trained...to analyze their data to produce systematic descriptions of a people’s lifeway or culture.” James, cited in Carlson et al. (1995: 17), however, define ethnography in more detail, as “...the study of culture from within, the attempt through field observation to record how individuals perceive, construct, and interact within their social and economic environment”. An ethnography paints a portrait of a cultural group or people (Creswell, 1998).

As a qualitative method or perspective, ethnography can rightfully be considered an offshoot from efforts to counter some of the shortcomings of empiricism/ positivism. According to Hammersley & Atkinson (1983: 4), “ethnographers have developed an alternative view of the proper nature of social research, often termed ‘naturalism’ ...and naturalism promotes ethnography.” Hence the terms ‘naturalistic study’ and ‘ethnography’ have sometimes been used interchangeably (Jessor, 1996). Jessor’s (1996: 5) detailed exposition of ethnography helps to put this into better perspective:

Ethnographers do, after all, concern themselves with extensive, naturalistic description of settings and contexts, with interpreting the meaning of social behavior and interaction, with understanding the perspective of the actor, the subjectivity of the Other, and with being able to narrate a coherent "story" of social life in which it is persons who have agency and who adapt and change with time and circumstances.

According to Jessor (1996: 5), “each of these aspects of qualitative inquiry can be seen as responsive to one or another of the felt shortcomings of mainstream research...”.

Ethnography developed from cultural anthropology (Morse & Field. 1995). It is a holistic, contextual, and reflexive (Morse & Field, 1995; Fetterman, 1989) approach that focuses on a people’s lifeway or culture (Jessor, 1996; Carlson et al., 1995; Morse & Field, 1995; Fetterman, 1989) in order to understand their meanings, patterns of thought and behaviour, relationships, and explanations (Carlson et al., 1995; van Manen, 1997; Morse and Field, 1995; Fetterman, 1989) “from the insider’s point of view” (Morse &



Field, 1995: 26), within a natural setting (Creswell, 1994). The product is usually a systematic description of a particular culture or aspect of thereof.

The focus on the insider's view in ethnography is paramount. "Rather than studying people, ethnographers learn from people" (Morse & Field, 1995: 26). At the heart of ethnographic research is the desire to understand the *emic*, or the native's point of view (cf. Morse & Field, 1995; Fetterman, 1989). It is this insider's/emic perspective of reality that enables an outsider to understand why members of a social group do what they do, and accurately describe the situations and behaviours (Fetterman, 1989). However, ethnographers also endeavour to make sense of data collected from an *etic* or external social scientific perspective (Fetterman, 1989). Therefore, "...ethnographers start collecting data from the emic perspective, ...[then] try to make of what they have collected in terms of both the native's view and their own scientific analysis" (Fetterman, 1989: 30).

The influences of the other theoretical perspectives (i.e., symbolic interactionism and phenomenology) utilized in this study are quite apparent. Jessor (1996: 7) has observed that ethnography has an inherent interactionist perspective, and has a commitment to social constructionism. Hammersley & Atkinson (1983) have also noted the influence on ethnography/naturalism of philosophical ideas from symbolic interactionism and phenomenology.

Both the holistic orientation and focus on the insider's view of reality characteristic of ethnographic research impel ethnographers to spend a considerable time period in the field as well as use multiple (qualitative) methods of collecting data, such as participant observation, semi-structured interviews, unstructured/informal interviews, and field notes (cf. Jessor, 1996; Morse & Field, 1995; Creswell, 1994; Fetterman, 1989; Hammersley & Atkinson, 1983). The effect of multiple data sources (methods triangulation) is regarded as a positive contribution to the trustworthiness of the data, and will be discussed below under subsection 'Rigor'.

In this study, an ethnographic approach was used to investigate perceived, provided and received/utilized supports, particularly to gain access to practices of social support within a cultural context (in a broad sense). I used culture at a lower level, to examine the practices of caregivers (i.e., the culturally patterned behaviours), as well as



their conceptions of social support, and how it interacts with social stigma. In other words, cultural interpretation involved describing what I heard and saw within the framework of the caregivers' (as a social group) view of reality. As dictated by ethnographic standards, I used more than two qualitative methods (discussed below) to collect data. I also used ethnography both as a process (the prolonged contact with participants, doing interviews), and as an outcome (the analysis and write-up).

### Phenomenology

Much like ethnographic studies, phenomenologically oriented studies are generally inductive in approach. Phenomenology takes as its main aim the analysis and description of everyday life – the life world and its associated states of consciousness (Abercrombie, Hill & Turner, 1994). It informs us, when carrying out a study, to bracket off judgments about social structure, that is, making no assumptions about the existence of causal powers of social structure. To be more specific, phenomenology is the study of experiences and the ways in which we put them together to develop a worldview (Marshall & Rossman, 1995). Unlike ethnography, which seeks to explicate meanings specific to particular cultures, phenomenological research describes “the experiential meanings we live as we live them”, our life worlds (van Manen, 1997: 11; Morse & Field, 1995). It focuses on a concept or phenomenon, and “...seeks to understand the meaning of experiences of individuals about this phenomenon” (Creswell, 1998: 38).

Patton, cited in Marshall & Rossman (1995), identifies three basic steps to phenomenological inquiry: *Epoche*, phenomenological reduction, and structural synthesis. *Epoche* is the period in which a researcher must examine herself/himself in order to identify personal biases and remove all traces of personal involvement. *Phenomenological reduction* concerns the bracketing of the rest of the world and any presuppositions with which a researcher approaches the subject of study. According to Patton (in Marshall & Rossman, 1995: 83), this enables the researcher to identify the phenomenon in its “pure form, uncontaminated by extraneous intrusions”. The data are then clustered around invariant themes that this reduction has allowed the researcher to identify, and to identify the textual portrayal of these themes. The final stage is called *structural synthesis*, and involves the articulation of the ‘bones’ of the experience of the



phenomenon and the description of its deep structure (Patton, in Marshall & Rossman, 1995).

An inherent assumption within phenomenology is that there is a ‘structure and essence’ to shared experiences that can be determined (Patton, in Marshall & Rossman, 1995). This assumption implies that phenomenology can be referred to either as ‘the subject matter of inquiry’ or ‘the methodology of the study’ (Marshall & Rossman (1995), or makes it a method, a philosophy and an approach (Morse and Field, 1995: 22; 151; Creswell, 1994). As a philosophy, phenomenology is characterized by a focus on understanding the ‘lived experiences’ of participants, and, “as a method the process involves studying a smaller number of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning” (Creswell, 1994: 12). Through this process, the researcher ‘brackets’ his/her own experiences in order to understand those of the informants (Creswell, 1994); hence the emphasis on interviews without structure, so that no presumptions about how participants view something are brought into the study (Neutens & Rubinson, 1997).

Another key concept in phenomenology is ‘existence’, as ‘being in the world’ (Morse & Field, 1995). This “...phrase acknowle[dges] that people are tied to their worlds (embroiled) and are understandable only in their contexts” Morse & Field, 1995: 157). A phenomenologist, therefore, seeks a deeper and fuller meaning of the participants’ behaviour and/or experience of a particular phenomenon (Morse & Field, 1995) in their natural context, through the eyes of the participants in the study (Neutens & Rubinson, 1997). Using Weberian terminology, this is called *verstehen*, which is the interpretative understanding of human interaction (Neutens & Rubinson, 1997).

The focus on human interactions in their natural context in this perspective is consonant with the qualitative approach. In fact, the phenomenological perspective is ever present as a theoretical framework in qualitative research (Neutens & Rubinson, 1997), because as a human science it is a form of qualitative research (van Mann, 1997). For this reason, data collection takes the form of in-depth conversations/interviews (Morse & Field, 1995).

Phenomenology was used in this study both as a philosophy and a method, guiding the research design, gathering and analysis of data. This perspective helped me



to understand the everyday ‘lived experiences’ of family caregivers and home-based care workers, particularly how social support interactions (i.e., human behaviour), occur in the context of relationships to things, people, events, situations and culture.

This was made possible by the fact that the constructivist/naturalistic approach is consonant with, and draws from the philosophical, sociological, and anthropological ideas (such as symbolic interactionism, phenomenology and ethnography), that guided the study in a complementary manner. Although they start from different points, these various approaches argue that the social world cannot be understood by the subsumption of social events under universal laws. This is because “...human actions are based upon, or infused by, social meanings: intentions, motives, attitudes, and beliefs” (Hammersley & Atkinson, 1995: 7). In fact all these paradigms/methodologies feed into each other. For example, “the typical model for ethnographic research is based on a phenomenologically oriented paradigm” (Fetterman, 1989: 15).

### **Sampling Procedures**

A number of sampling procedures and techniques were followed in this study. All sampling methods and techniques employed were commensurate with the philosophical principles of qualitative research.

#### *Samples*

The total sample of urban caregivers of PWHA was 14 (11 female & 3 male). This comprised 9 caregivers from two adjacent low-income suburbs of Mabvuku and Tafara, on the eastern outskirts of Harare. Contact with these caregivers was made through Mashambanzou Palliative Centre based in the suburb of Waterfall, Harare. The remaining 5 urban-based caregivers were from low-income suburbs in a satellite town called Chitungwiza, about 20 kilometres south of Harare. Out of these 5, 2 were from a suburb called St. Mary’s, 1 from Zengeza 3, 1 from Zengeza 4, and 1 from Unit J in Seke. These 5 were recruited through three different Red Cross centres in Chitungwiza, all attached to local clinics/health centres (Seke South Clinic, Zengeza Clinic and St. Mary’s Clinic).



The rural sample comprised of 9 (8 female and 1 male) caregivers of PWHA, all living within a radius of about 11 kilometres from a rural centre called Mutoko, which is about 180 kilometres northeast of Harare. Four of these were recruited through the Mother of Peace Orphanage, situated about 5 kilometres from Mutoko centre, just beyond the ‘famous’ Mutemwa Leprosy Centre. The remaining 5 caregivers were recruited through a local volunteer home-based worker, who is HIV positive herself.

The urban sample of institutional support personnel that support PWHA and their caregivers was 5 and they were all female. One was from Mabvuku suburb, and 4 were from Chitungwiza town. Out of these 4, 1 was based at Seke South Clinic, 1 at Zengeza Clinic, and 2 at St. Mary’s Clinic. The rural sample comprised of two female home-based support staff. One was a volunteer home-based worker, who was also HIV positive, and a leader of a local support group for PWHA. The other was a local support group coordinator for PWHA, attached to the Mother of Peace Orphanage, and she was also HIV positive.

Because this is a qualitative study, which emphasizes content and depth of the interviews rather than the quantity, a total sample of 22 caregivers is consistent with guidelines for sample size provided by qualitative researchers (Sandelowski, 1995). Polkinghorne, cited in Creswell (1998: 54), states that the number of participants in a qualitative study range number from 5 to 25. Also, because the main focus of the study was on family caregivers, institutional support personnel were only required to verify and ascertain administered support. Therefore, the total seven home-based support workers were considered adequate for this purpose.

### Sampling criteria

The following are the important inclusion/exclusion criteria used in the selection of family primary caregivers and institutional support personnel:

1. Participants had to be able to communicate fluently in either English or ‘Shona,’ the main dialect in Zimbabwe.
2. Only consenting primary family caregivers were eligible to participate.
3. Due to the small numbers of community-based care workers, their selection was based on consent and availability.



4. As contacts were facilitated by support organizations, effort was made to balance the selection by gender, age, and marital status in both urban and rural samples. However, the number of prospective and consenting participants determined the final samples.
5. Potential participants were excluded on the basis of current state, e.g. members of grieving families, and the condition of the illness. That means caregivers of patients who had been diagnosed HIV, but were still strong enough to go about their daily activities without needing much support were excluded.
6. Participants had to be above eighteen years of age and above.

### Sampling methods

The Zimbabwe AIDS Network (ZAN), a non-governmental organization that helps to facilitate networking between organizations that support PWHA as well as support groups founded by PWHA was the first to be contacted for referrals to institutions that support PWHA and their caregivers. Unfortunately there were not many organisations that supported PWHA available. There were more support groups of PWHA than organisations that support PWHA and their caregivers. From ZAN I then obtained three referral letters to organizations that I thought would give me the best mix of low-income (i.e., Mashambanzou Palliative Centre and Red Cross Society) and middle-income (i.e., The Centre and Red Cross Society) participants. I also hoped to get a good mix of participants from different ethnic groups from these three organisations. Therefore, purposive sampling procedures started with the selection of supporting agencies.

The Centre, which is a non-governmental organisation that supports PWHA was hoped to yield middle class participants from diverse cultural/ethnic groups. The official that handled my application indicated they would need to consult with the people involved in counselling PWHA, to find out if they would consent to the study. After a week had passed and no call had come, I visited The Centre again to enquire about the status of my application. That was when I was notified that the counsellors had declined to assist me. In ethnographic language, the 'gatekeepers' kept their gates shut. The



reason was that they anticipated that the study would arouse some emotional turmoil in their 'clients', a problem they would have to deal with after the study was completed. By then it was too late in my schedule to get back to ZAN and ask for another reference letter to another potential organization dealing with middle class caregivers.

Mashambanzou was characterized by a fair amount of bureaucracy before the approval. Although the sisters (church as well as SRNs) who run the centre thought this was a worthy cause, they passed the buck to the community nurses responsible for home visits. According to them, the organisation strictly followed a participative approach whereby the nurses took part in making decisions regarding matters that affect their work. My research was therefore to be given to these outreach teams, and I was to be notified by phone. When that phone call did not come after a week of waiting, I visited the centre again, and I was told that the outreach teams disapproved on the basis of the incentive I was offering (ZW\$200/ CDN\$6, plus a pair of gloves & a disinfectant). According to the directors of the centre and the nurses, this was too little for these poor people, considering the value of what they had to give in terms of knowledge. It was then too late to go back to ZAN to get a referral to another organization. Although I did not have funds for incentives in my budget, I agreed to up the monetary incentive to ZW\$500 (CDN\$15). This offer was taken back to the outreach teams, and an approval came slightly more than a week after. As it turned out, all five or so outreach teams were in charge of supporting PWHA living in low-income neighbourhoods, and I got attached to a team responsible for Mabvuku and Tafara suburbs.

About two and a half weeks of hitting my head against bureaucratic red tape resulted in getting approval from The Secretary of the Zimbabwe Red Cross Society. This period was characterized by numerous trips between the head office (where I was 'bounced' from one official to the other, sensing some diffusion of responsibility here) and the Harare Provincial Office (where they kept referring me back to head office), which are only three streets apart. One major cause of delay was the need to follow written bureaucratic procedures. Even after head office gave a go ahead, the provincial office would not refer me to the district/local office before they received a written letter stating the head office's commitment, again, another example of the dysfunctions of bureaucratic procedures where members tend to follow rules in a ritualistic manner.



Another reason for the delay was that in both offices, officials frequently went out of town for official business, and in their absence no one could assume responsibility. It also transpired during this time that The Red Cross Society did not have a home-based care program running in Harare but Chitungwiza, a satellite town on the outskirts of Harare, where the majority of inhabitants are of low-income status. However the officials welcomed the study without any reservation because they hoped it might help them to improve the operations of their home-based care programme. Once approval was granted, I was ready to contact the local office in Chitungwiza so that potential participants could be contacted.

Approval from Mashambabzou Palliative Centre (MPC) preceded that from Zimbabwe Red Cross Society. Fearing a possible disapproval from the Red Cross Society (RCS), I went ahead and procured a sample of 10 participants from Mabvuku and Tafara suburb, with the help of an outreach nurse working for MPC who acted as the 'gatekeeper'. Research had been under way for about a week, with all initial contacts with potential participants made, and consent forms signed, when approval was granted by the RCS. Although my initial target was a sample of 10 urban caregivers, this offer provided me with an opportunity to make the sample more heterogeneous with the inclusion of participants from other low-income neighbourhoods. With the prospect of broadening the knowledge gained, or rather, the caregivers' constructions of reality, I decided to get 5 more caregivers from Chitungwiza town.

All urban caregivers were purposively sampled through contacts with institutions that support PWHA. Purposive sampling is where "the researcher employs his/her own discretion to select the respondents who best meet the purposes of the study" Neutens & Rubinson, 1997: 125). While the outreach community nurse from Mashambanzou went on her routine visit to Mabvuku and Tafara suburbs, distributing essential foodstuffs and other cleaning consumables, I tagged along. She was to be my chief informant (or 'gatekeeper'), facilitating my entrée into the community. We visited all the homes with PWHA that they were currently supporting. The role of the nurse was to introduce me to the family members and help me to decide who was eligible to participate, basing our judgments on the inclusion-exclusion criteria, and demographic variables/criteria provided that we had discussed before.



Out of a total of 16 homes visited, 3 potential caregivers were not present in their homes twice in succession, and were ruled out. The other potential caregivers for one HIV person were children below 18 years of age, and they were also ruled out. One potential female caregiver who was left out because she did not seem receptive enough, and, the last female to be excluded (but had consented) resided at the same address where another consenting caregiver was looking after 3 siblings, all HIV positive. The experiences of the later were anticipated to be more insightful, due to the amount of the caregiver burden involved. Only 2 potential male caregivers were available. They consented and were included in the sample in an effort to balance the gender criteria. Out of the total 10 consenting caregivers, one female caregiver in Mabvuku had her patient pass on two days after the socio-demographic data had already been collected. For this reason she was dropped out of the study, bringing this sub-sample to 9.

The same procedure was used to select participants from Chitungwiza town. Although I was looking for a smaller sample in Chitungwiza, it was difficult to get the numbers I ended up with because of unavailability of enough clients registered with the RCS. Most of the clients registered with them had passed away before the study commenced, as evidenced by recordings in a register at Seke South Clinic, which showed 'deceased' in red ink below numerous entries. Some patients had moved to other suburbs, as well as to the rural areas, where most patients end up anyway, owing to the higher cost of living in cities and towns. However, these home-based care workers also looked after patients suffering from other chronic conditions that were not of my interest.

Another possible reason why the RCS had less PWHA than MPC registered under their care might have been the fact that MPC has infrastructural resources (e.g., pick up trucks for a more effective out-reach programme), and handouts to offer their patients. Whereas the RCS home-based care workers either walk or use public transport to visit their patients, their working hours have been reduced to 4 per day, owing to shortage of funds in the society's coffers, which mostly comes from donors. These factors might be acting as disincentives, causing home-based workers to limit the amount of contacts with registered PWHA, or avoid making new contacts. Moreover, the RCS can only offer household gloves to PWHA and/or their caregivers, and, in most cases these have to be collected by clients from their RCS local offices.



As a result, the home-based worker (HBCW) from Seke South Clinic could only connect us with 2 caregivers, the one in Unit J, Seke, and the other in Zengeza 4. The HBCW from Zengeza Clinic was able to connect us with one caregiver, and the two HBCWs from St. Mary's Clinic connected us with 2 caregivers. All 5 caregivers were visited on the same day, and met the selection criteria. Deeming the numbers adequate for the study, no more caregivers were sought after this.

When a potential participant was visited, the HBCW (the 'gatekeeper') introduced me to them and briefly explained the purpose of my visit. With the Mabvuku and Tafara sub-sample, all those contacted expressed their interest to be part of the study on that first visit. It was during the second visit that I explained my study to them in detail, as well as indicate to them that I would be giving them ZW\$5000, a pair of gloves and a disinfectant as a token of appreciation for taking part in the study. The consent form was signed thereafter.

The same approach was used with the Chitungwiza sub-sample, with a slight variation in that, soon after each potential participant expressed interest, the HBCW moved out of the picture and I explained the study in detail and sought written consent. Sociodemographic data were also collected on the same day.

Purposive sampling was also used to select a HBCW in Mabvuku. The senior HBCW responsible for coordinating and training of volunteer HBCWs that work in support of MPC initiatives was interviewed. It was felt that she was in a strategic position to have better knowledge of what was happening on the ground than the outreach nurse who did not leave in the community. In Chitungwiza, convenience sampling was used to select the 4 HBCWs that were interviewed. Convenience sampling is a sampling technique whereby participants are selected because they are available (Wolcott, 1994: 75). Owing to the shortage of funds within the organization, HBCWs worked fortnight shifts, four hours per day. Therefore, the HBCWs that I found on duty, and subsequently connected us with caregivers were asked for an interview. Fortunately all agreed to participate.

The selection of the rural sub-sample was an entirely different ball game. The District Hospital that was expected to help with recruitment was not in a position to do so. It took about a week and two days to establish that they would not be able to help.<sup>3</sup>



When the District Nursing Officer was finally available the following week, she gave me a referral letter to three health centres in the district where she was confident the local nurses would be able to help me. Unfortunately, my first visit to one of the health centres drew a blank. Rather than take a gamble and try the other three, I decided to try the other person indicated on the referral letter. This was the volunteer HBCW and leader of a support group of PWHA who finally acted as my chief informant (or 'gatekeeper').

Using the inclusion/exclusion criteria that I explained to her, we both set on a journey through rough country terrain to locate suitable potential participants. Purposive sampling was utilized, yielding 4 participants. Left out of consideration were caregivers of patients whose illnesses the HBCW was not sure were HIV/AIDS related. Also left out were caregivers of HIV positive persons that were able to look after themselves. Since I was running out of time, I combined the first two activities in my initial visit. The same procedure as that followed in Chitungwiza was used: introductions and asking for cooperation by the HBCW; a detailed explanation of the project by myself, mostly in the absence of all present family members; signing of consent forms and collection of socio-demographic data. The unstructured and semi-structured interviews were conducted on separate days. However, unlike with the urban sample, photographs were taken on the same day the semi-structured interviews were done. This change in strategy was necessitated by the countrywide shortage of petrol, which I could only get in Harare on my way in. However, the cutting down of visits from five to three was compensated for by longer periods of time spent per visit, during which observations were made, and rapport established.

The other half of the rural sub-sample (No.=4) was obtained through the help of a new chief informant, the local coordinator of support groups of PWHA, affiliated to the Mother of Peace Orphanage. The same selection procedures as those used above were used to select the first caregiver. This coordinator did not have enough knowledge of the location of many of the members of particular local support groups.<sup>4</sup> Therefore; the *snowball sampling* procedure was utilised. The first caregiver gave us directions to a family relative that lived by the foot of a mountain across the river. Then we drove about 15 kilometres in a different direction to find a leader of another support group whose address the coordinator was not particularly sure about. When we found her and she



consented to being part of the study, she in turn led us to another member of a different support group, 6 kilometres further into the hinterland. Bias in the use of this sampling technique was minimised by the fact that two participants were purposively selected, and they in turn identified two others. The recruitment strategy and sequence of interviews were the same as those used with the initial 4 caregivers recruited from the northern part of the rural area. This gave me the total rural sub-sample of 8.

The sampling principle of *adequacy* (Morse & Field, 1995) was applied in this case. New participants were hard to contact, owing to the wide geographical space and limited supplies of petrol. However, the most important factor determining the size of my rural sample (No.=9) was the fact that enough data were deemed available to develop a full and rich description of rural caregivers' experiences of Social support. To use Morse & Field's (1995: 80) words, "...the stage of saturation ha[d] been reached." That meant no new data would emerge by conducting further interviews. At this point I saw no reason to match the rural sample size with the urban sample (No.=14), nor was there any need to achieve the sample size put down in my proposal (No.=10).

The recruitment technique of home-based care workers was again convenience sampling. There was no one else in the community doing that work, apart from the two participants that had accompanied me and introduced me to the caregivers in my sample.

The selection of participants (i.e., both caregivers and HBCWs) for this study was also based on the urban-rural divide. Therefore, two quotas had to be established. Quota sampling is whereby a researcher "...determines which strata are relevant to the investigation and then proceeds to establish a quota for each stratum that is proportionate to its representation in the population," (Neutens and Rubinsen, 1997: 124). Other desired and important quotas/strata were male/female, socio-economic class, ethnicity, and marital status. The one that was not achieved, because of reasons explained above, was socio-economic status. The ethnicity quota was not fulfilled as had been anticipated. A few nationals, formerly from Malawi and Mozambique were part of the sample, but there were no participants of European or Indian descent.

In total, four sampling techniques were used in this study: Purposive sampling, quota sampling, convenience and snowball sampling. The overarching technique, however, was purposive sampling, stratified in various ways pertinent to the research



issues. According to Morse and Field (1995), the two principles that guide qualitative sampling are 'appropriateness' and 'adequacy'. The principle of "appropriateness is derived from the identification and use of ...participants who can best inform the research according to the theoretical requirements of the study" (Morse & Field, 1995: 80).<sup>5</sup> In this study, the choice of sampling techniques and participants were deemed appropriate for the purposes of answering the stated research questions. They were also regarded as commensurate with the principles research principles embodied in the theoretical perspectives utilised in this study.

## **Methods of Data Collection**

The choice of methods (and techniques) of data collection/ fieldwork are influenced by the framework(s) chosen by the researcher (cf. Creswell, 1998; van Manen, 1997; Marshall & Rossman, 1995; Wolcott, 1994). According to van Manen (1997: 27), just the notion of method itself "...is charged with methodological considerations and implications of a particular philosophical or epistemological perspective." In this study, the choice of procedures, methods and techniques described below were conceived within the general orientation characterizing the qualitative approach and the methodologies/perspectives discussed above. The choice was also influenced by the nature of the research questions under study, a noteworthy practice noted by researchers such as Lambert et al. (1995), and Marshall & Rossman (1995). The questions could only be answered by using qualitative methods.

The interpretive and naturalistic nature of qualitative research infuses a multimethod focus in it (Denzin & Lincoln, in Creswell, 1998). The use of multiple methods has become popular in the social sciences in this "...postpositivistic climate of epistemological openness and methodological pluralism" (Jessor, 1996: 5). However, its significance comes from the need to rely on the convergence of findings from multiple and diverse research procedures in order to enrich findings (Morse & Field, 1995; Swanson & Chapman, 1994; Lambert et al., 1995; Jessor, 1996). Thus, methodological choices can be strengthened by 'triangulation', which is "...the sequential or concurrent



use of [different] methods [to] improve the validity, generalizability, and confidence in research findings and their implications..." (Lambert et al., 1995: 3).<sup>6</sup>

In this study, there was sequential (structured interview, unstructured interview, and semi-structured interview) and concurrent (interviews combined with observation) use of methods. According to Marshall & Rossman (1995), combined with observation, interviews allow the researcher to understand the meanings people hold for their everyday activities." This triangulation was done to improve the quality of data and the accuracy of findings (a matter to be discussed later in this chapter). And, commensurate with the prerogatives and principles of naturalistic inquiry, all interviews were conducted at the homes of participants.

### Structured Interview (Socio-demographic Data)

Morse and Field (1995) advise that a successful qualitative interview depends on the trusted relationship established at the beginning. They suggest that this can be achieved by, among other things: a) letting the participant choose the location of the interview, b) beginning with small talk, c) starting the interview with the consent procedures, and d) *beginning by asking for demographic data*.

Going into this study I made the assumption that there are systematic patterns to the way caregivers create meaning in their lives, perceive their place within their social networks and society (at large), and behave. I also assumed that education, gender, ethnicity, class, geographic context (etc), might pattern that knowledge.

My first meeting with each participant, therefore, was aimed at asking for consent, and completing the socio-demographic questionnaire (Appendix E). With the backing of this socio-demographic data, I hoped to gain an understanding of caregivers' experiences as well as delineate the wider socio-political context in which caregiving and social support take place. Demographics were also essential in securing a comparative baseline data about caregivers' circumstances and experiences.

I completed the questionnaire for every participant, and this took 20 minutes on average. This was done in order to save time, and, the fact that most of the participants were illiterate or semi-illiterate it saved them from embarrassment. After the collection



of demographic data the conversation drifted to small talk, aimed at making each participant to feel that they had given out personal information to a ‘trusted friend’.

Equally important on my agenda during this meeting with a participant, though, was establishing rapport with participants, paving way for a smoother transition into the next two interviews. This was hoped to be the foundation for a continuous move towards an intimate and trusted relationship during the period of the study.

### Unstructured Interviews

I used interviews in this study to classify and organize each caregiver’s perception of reality. Unstructured interviews focused on the accounts of experiences of caregiving, and formal and informal social support (see Appendix F). Only a few general topics were covered in depth, with respect being paid to how participants framed and structured their responses. A certain degree of systematization was employed in questioning participants. According to Marshall & Rossman (1995), this is necessary in a “multi-site case study or when many participants are interviewed.” I had a good number of participants, and I had urban participants from three different suburbs and participants from a rural area. I used data obtained from these interviews to modify provisional semi-structured interview schedule to for the next visit. The information also formed the basis for the probes during the subsequent semi-structured interviews.

A purposive sample of 22 consenting caregivers was interviewed at a third meeting with each participant (second meeting in the case of rural participants). The interviews were conducted at participants’ homes, where participants were presumed to be more comfortable and forthcoming with information. All interviews were audiotaped, with the permission of each participant. Audiotaping and field notes are considered to be some of the crucial methods of recording data in ethnographic research (Hammersley & Atkinson, 1983: 145). Field notes were also written after each interview.

I made every effort to make each interview seem like a casual conversation. The interview process was, therefore, a mixture of conversation and embedded questions. In some cases, some questions or probes resulted from comments by the participant. With each of the general questions as well as the probes, I made sure to wait for the most appropriate time to ask them during the conversation. During the interview process, I



always made sure to begin with small talk in order to put the participant at ease. Moreover, going straight into the question mode is a threat to validity (Morse and Field, 1995). Then I moved on to non-threatening questions embedded in conversation, before posing highly personal and potentially threatening questions concerning their social relationships and the disease their patient was suffering from. I used this strategy to develop a healthy rapport before introducing sensitive topics.

Unstructured interviews are a crucial method of gathering data in qualitative research. They are variously called: in-depth interviewing (Marshall & Rossman, 1995); 'conversation with a purpose' (Kahn & Connell, in Marshall & Rossman, 1995); open-ended interviewing or a free-flowing conversation or informal interviewing (Carlson et al, 1995). Conversation flows freely in reference to a particular topic, and these interviews serve "...as a means of determining how people talk about or perceive [and express] various aspects of their lives and how they categorize things" (Carlson et al. 1995: 14).

I conducted unstructured interviews with seven (5 urban-based and 2 rural-based) home-based care workers, where the 'conversation' flowed freely, covering some unanticipated but relevant topics. These acted as my key informants and helped me to gain entry into the communities and participants' homes. The use of key informants is particularly relevant in ethnographic research (Morse & Field, 1995). I also used the same procedure for asking for consent and creating rapport used with caregivers with home-based care workers. Interviews with home-based care workers were akin to what Marshall & Rossman (1995: 83) call 'elite interviewing'. According to them, this is:

[A] specialized case of interviewing that focuses on a particular type of interviewee. Elite individuals are considered to be the influential, the prominent, and the well-informed people in an organization or community and are selected for interviews on the basis of their expertise in areas relevant to the research.

Although home-based care workers are probably the lowest in their organizational hierarchies, their selection was based on their expertise in dealing with caregivers on a day-to-day basis. These interviews also followed a conversational format.



## Semi-structured Interviews

Semi-structured interviews are “verbal approximations of a questionnaire with explicit goals” (Fetterman, 1989: 48), to be used “when the researcher knows most of the questions to ask, but cannot predict the answers” (Morse & Field, 1995: 94). They are “useful because this technique ensures that the researcher will obtain all information required (without forgetting a question), while at the same time gives the participant freedom to respond and illustrate concepts” (Morse & Field, 1995: 95).

Semi-structured interviews were conducted after the completion of unstructured interviews to allow the construction of relevant questions based on the already procured information. It is generally recommended that semi-structured interviews be used as a second interview, when the fieldworker comprehends the fundamentals of the phenomenon under study from the “insider’s” perspective (Fetterman, 1989; Morse & Field, 1995). At this point, the second interview is considered a little more directed, and questions are more likely to conform to the participant’s perception of reality than to the researcher’s (Fetterman, 1989; Morse & Field, 1995).

Based on prior tentative questions and knowledge from unstructured interviews, the questions in the semi-structured interview were carefully prepared, in a logical (e.g., from general to specific), and where possible, in chronological order (see Appendix F). I constructed each question to address only one aspect of a topic, in order to avoid double-barreled questions. I also left almost all questions open-ended in order to leave participants to provide as much information as possible. Questions generally focused on the types available and received support, as well as participants’ caregiving experiences. As with unstructured interviews, I always started each interview with - small talk, a brief recap on a few issues touched on in the previous interview - a non-threatening icebreaker. All questions were followed up with one or more probes whenever necessary, in order to tap more comprehensively into participants’ experiences. All semi-structured interviews were also tape-recorded, with the consent of participants.

However, half way through the study, at the beginning of rural interviews, I decided to add about 5 more questions centred on food security (i.e., harvests, cattle, goats, etc), and few others on things such as caregiving tasks, and proximity to a health facility. I realized that such questions would obtain valuable information central to the



topic, particularly in the rural areas where agricultural activities are crucial for survival. However, some low-income urban dwellers illegally carve (for themselves) plots on unutilized municipal land on the fringes of their suburbs for agricultural activities. In addition, most town dwellers maintain a second home in their rural area of origin, where they continue to cultivate crops.

For these reasons, as well as the fact that the other questions such as those regarding caregiving tasks would also be applicable to an urban sample, I subsequently went back to all urban participants to ask those particular questions after completion of the rural portion of the study. Since I had 'left the door open behind me' after my last interview with them, by letting them know I might visit them again if there was anything important I might need from them, reentry was easy. Most were actually anticipating this visit, such that when almost a month went by before I 'resurfaced' they began to think I had lied to them, much to my relief that I had finally made it. However, two caregivers were unavailable two days in a row, and I had to do without them. One caregiver had separated with her HIV positive husband, and the other HIV positive caregiver had gone for an AIDS awareness workshop organized by the Zimbabwe National Network for People Living with HIV/AIDS (ZNNP+), of which she is an active member.

### Observation

Observation is one of the primary and critical methods in qualitative research (Neutens & Rubinson, 1997; Morse & Field, 1995; Creswell, 1994, 1998; Marshall & Rossman, 1995). Observation "...entails the systematic noting and recording of events, behaviors, and artifacts (objects) in the social setting chosen for study (Marshall & Rossman, (1995: 79), in order to "...add...breadth to research and provide...answers to contextual questions that cannot be answered by interviews alone" (Morse & Field, 1995: 105). It is in keeping with the philosophical underpinnings of qualitative research because it enables a holistic description of events and behaviour (Marshall & Rossman, 1995), since "...observational data are collected in a naturalistic setting [and] the researcher does not manipulate or control people or other significant things related to the study" (Neutens & Rubinson, 1997: 145; Marshall & Rossman, 1995).



The observation method was used during the entire study, from the first visit to each participant's home, to the last one. That means, even during each of the three interviews, observation played an important role as I noted body language and affect in addition to the participant's words. This enabled me to move beyond the perception of the participants. Outside the context of each interview, however, general observations were also made of general interactions between the caregiver and the patient, and anybody else that was present in order to note recurring patterns of behavior and relationships (and quotations of participants wherever possible). Also under observation and worth noting with each visit were other things that a tape-recorded interview could not pick up, such as the physical setting, dimensions of space, household furniture and personal belongings. Hence, ethnographic observations of the conditions in the home and how caregivers go about their caregiving and other day-to-day responsibilities were considered crucial.

With the urban sample, the initial visit to each participant's home (and subsequent visits in the rural areas) was made in the company of either a community nurse or a home-based care worker (HBCW), and in the rural areas they were done in the company of a HBCW. Their interactions with family caregivers were also considered noteworthy, and were observed. This provided me with a window of opportunity to understand the context within which these community workers operate, and immensely supplemented data interviews of both caregivers and HBCW.

I would say in a number of instances my style/technique of observation leaned more towards '*observer as participant*'. According to Morse & Field (1995: 108), this is a level of participant observation whereby "... the majority of the researcher's time [is] spent observing and interviewing and minimal participation in the work role, provides more freedom to do research with less conflict." This is so because outside the context of the interview process I often times helped out with some routine caregiving chores, as long as I was not getting in the way, and I felt that it helped to build a relationship of trust and friendship between the caregiver and myself.

Field notes: Bogdan & Bikken, cited in Morse & Field (1995: 112), describe field notes as "...a written account of the things that the researcher hears, sees,



experiences, and thinks in the course of collecting or reflecting on data in a qualitative study.” They “...consist of jottings of salient points...[and] take the form of reconstructions of interactions, short conversational excerpts, or descriptions of events” (Field & Morse, 1995: 112). Field notes supplement other forms of data gathering (Neutens & Rubinson, 1997; Morse and Field, 1995; Marshall & Rossman, 1995; Hammersley & Atkinson, 1983).

Some scholars note ‘field notes’ as a separate data gathering technique, but I have chosen to place it under observation because, although field notes were done to supplement interviews, much of the notes were done in the process of reconstructing observed events/phenomena. Some were also based on informal and incidental discussions with participants during the duration of the study. All field notes followed the form given by Morse & Filed (1995): participant code#; interview date, time; people present; description of the environment (including personal belongings, etc.); nonverbal behaviour, and other relevant things.

To minimize data loss and memory distortion, as urged by Morse & Field (1995) and Neutens & Rubinson (1997), field notes were written soon after a visit to a participant’s home, and/or soon after an interview, before the next interview was conducted. Therefore, soon after an interview I would drive off, park the car around the corner and jot down my notes while things were still fresh on my mind. Whenever convenient, sometimes I would excuse myself, and under the pretext of getting something from the car, I would lean into the car and quickly jot a quotation of what somebody had just said (verbatim). This was done only under circumstances whereby it would not disrupt any social interaction. However, observation-based notes were easier to jot down during the collection of socio-demographic data. While going through the interview, it was much easier to jot notes about any observed phenomena in spaces between questions or in the margins of the questionnaire schedule. Field notes were worked up and expanded upon, with all the shorthand converted into long hand, back home before going to sleep. This was the time that I also put in my own insights.



## Photographs

To be able to provide a visual image of each context, particularly the home environment of each caregiver, I obtained consent to take one or two photographs of the caregiver. Some caregivers asked for their patients to be included in the photograph as well. In Morse & Field's (1995: 119) words, the photographs were taken in order "to provide an insight and knowledge about human conditions." The idea of taking photographs was introduced by an HIV positive urban-based caregiver who thought it would be a good opportunity for other people to know about the AIDS situation, as well as a possible means of showing their plight to the world and attract financial help. Besides, a copy sent to them would be a welcome addition to a collection of a few photographs on the wall. However, this was towards the end of my urban fieldwork. Therefore, I started taking photographs while doing my rural fieldwork, then came back to photograph the urban participants. Unfortunately, the initiator was not at home to 'benefit' from this endeavour, and exposures of the last four participants did not develop well.

## **Data Analysis**

Consonant with qualitative research procedures, data analysis started during fieldwork, when the transcription of the initial interviews redirected the approach to posing questions to participants as well as informed the development of semi-structured interviews. This is why "ethnographic analysis is iterative, [because it] build[s] on ideas throughout the study" (Fetterman, 1989: 88). This iterative process also enabled me to change data collection techniques. The day-to-day writing and reconstruction of field notes, whereby insights were recorded, was also part of data analysis. However, the data analysis process became comprehensive, and was speeded up following the completion of the transcribing process; and included: developing a coding framework, data coding (according to themes and sub-themes to indicate, for example, the specific types of supports naturally occurring) and synthesis, using NUD-IST software (QualitativeSolutions Research, 1997). Overall, data analysis was guided by the philosophical principles of the theoretical frameworks used in the study.



An overarching analytical strategy in this study derives from data source triangulation, involving an attempt to relate different sorts of data (i.e., field notes, unstructured interviews, semi-structured interviews, and observations) in such a way as to counteract various possible threats to the validity of the analysis. Information within documents was also triangulated to test for internal consistency (Fetterman, 1983), as was each participant's interviews and the accompanying field notes. In the final stage of analysis I had to reconfigure all field notes, socio-demographic data, and interviews, to draw an overall picture of how caregivers experience social support from these myriad minute details. Data analysis here is defined as "...the process of bringing order, structure, and meaning to the mass of collected data" (Marshall & Rossman, 1995: 111). Applied specifically to qualitative data, it "is a search for general statements about relationships among categories of data..." (Marshall & Rossman, 1995: 111).

The data analysis strategies were all based on two general mechanical forms noted by (Morse & Field, 1995: 128). The first one is '*interparticipant analysis*', or the comparison of transcripts from several participants. The second one consists of '*analysing categories*', sorted by commonalities, consisting of segments of transcripts or notes compiled from transcripts of several participants (Morse & Field, 1995).

Review of data: The first step taken, before any major analytical strategy was used, was a thorough review of all the data collected, in order to gain familiarity with the texts. This was facilitated by the task of transcribing the audiotapes. This is a common procedure recommended in the literature (cf. Carlson et al., 1995; Creswell, 1998; Hammersley & Atkinson, 1983). This initial 'familiarization' process was beneficial in two ways: It provided insights that led to the refinement of the questions in the semi-structured interview into categories that formed the coding framework in NUD-IST - necessary for content analysis, and it also provided a basis for the development of codes (themes and sub themes) used for phenomenological and ethnographic analysis on unstructured interviews and field notes, also in NUD-IST (non-numerical unstructured data indexing, searching, and theorizing *programme*).



## Matrices

The systematic review of information from field notes and interviews led to the creation of matrices. Matrices provide a simple, systematic way to compare and contrast data (Fetterman, 1989: 96), because one "...can compare and cross-reference categories of information to establish a picture of a range of behaviours or thought categories", as well as identify patterns in the data.

The first batch of matrices came from the initial sort of the socio-demographic data by item. That is, question one answers were sorted into two gender categories (either male or female), and the question two answers into six class intervals (interval width=10). This went on up to the last question, by which I had a table for each question on the questionnaire, making it much easier to see how many participants fell into each category at a glance. These tables formed the basis for simple descriptive statistics.

Next, social support structures were put into various categories, such as spousal/partners, family members, friends, neighbours, co-workers, professional sources. These categories became column titles on a spreadsheet. The rows consisted of other categories, such as emotional support, instrumental support, affirmational support, respectively. Then I plugged into the appropriate cells the participants' identifying numbers, so that I could see at a glance 'which participants received emotional support from neighbours' for example.

Then social support structures (as columns) were paired with the participants' identification numbers (as the rows). I then located the specific appraisals of support for each participant in the appropriate boxes or cells.

The next pair of variables to be paired in this way were: socio-demographic variables (including geographical location & network size) versus social support structures, with participants' identifying numbers going into the cells; socio-demographic variables (including geographical location & network size) versus social support functions, also with participants' identifying numbers going into the cells.

These cross tables/matrices provided an immediate picture of the range of variation across support receipt, the types of supports exchanged in different categories, geographic differences, and other valuable pieces of information. In addition, these data helped me to select particular cases from the whole sample for in-depth analysis, either



because of their overrepresentation, under representation. Matrices also helped to identify themes across sites (urban and rural) at a glance.

### Diagramming

In the process of categorizing research information, diagramming consists of identifying categories, and developing “...them into a visual picture of the categories that displays their interconnectedness” (Creswell, 1998: 158). The fieldwork experience (observations) recorded in the form of field notes, the general review of all gathered information, and the matrices construction exercise also led to another useful data reduction exercise: construction of diagrams. These displays of information became an immediate and easy way of placing social support experience in context. For example, social support was placed within the environmental context, showing the structural (macro, such as poverty, culture) forces impinging on support provision and receipt as well as the social processes (micro, such as social stigma, social exchange parameters) involved. Similarly, caregiving experiences were also placed in context, showing the macro factors that determine or increase (as well as decrease) the burden, and the effect caregiving burden has on social relationships in general (such as reduced interaction) and on health in particular (such as stress and muscle aches).

Later in the analysis phase, tree diagrams were also printed from NUD-IST. These were in the form of hierarchical trees of categories based on a ‘root’ node at the top and parents and siblings in the tree. This generated “...a ‘picture’ of the analysis, the major categories, the minor categories, and how the information from the text [was] grouped” (Creswell, 1998: 158).

### Social Network Analysis

The social network diagrams that were drawn with the assistance of participants were analysed separately, before being linked with other data. These were analysed for social network structure and functions, that were put into tables according to geographical location (urban versus rural; and according to suburb for urban dwellers).



## Content Analysis

Content analysis was performed on the semi-structured interviews. Content analysis specifies beforehand what it wants to know from the text (van Manen, 1997: 29), in my case, this was signified by the construction of semi-structured interviews. These were open-ended interviews, which served "...as a means of determining how people talk about or perceive various [caregiving and social interactional] aspects of their lives and how they categorize things" (Creswell, 1998: 14). This meant that the questions on the interview schedule alone could not be used as the only basis for creating the codes/categories for the coding framework used in NUD-IST. The initial review of semi-structured interviews led to the identification of words, phrases, descriptions, and terms central to the research. Some of these were words spontaneously used by the participants themselves, what Hammersley & Atkinson (1983) call folk terms. According to Hammersley & Atkinson (1983: 178), "...usually participant terms are always worth following up since they mark theoretically important or interesting phenomena." These words, phrases, and concepts, together with the questions from the semi-structured interview schedule, were used to construct the coding framework.

With the transcribed semi-structured interviews imported into NUD-IST as text files, the coding process consisted of reviewing each entire interview to identify and 'tag' text information and place it into a category (code). The codes were used for general comparative purposes and description purposes. However, 'chunks' of coded quotes were also used to supplement data from the thematic analysis of unstructured interviews in order to comprehensively portray the caregiving experience from the actors' perspective.

## Thematic and Ethnographic Analysis

Thematic analysis has largely developed from phenomenological research. It "...involves the search for and identification of common threads [usually abstract] that extend throughout an entire interview or set of interviews" (Morse & Field, 1995: 139; van Manen, 1997; Creswell, 1998). A careful reading and re-reading of the transcribed unstructured interviews and reflection on them, revealed the emerging themes on caregiving and social support receipt and provision. Themes generated were partly (to a



lesser extent) the concepts from the general questions posed to participants, and partly concepts indicated by the data (to a larger extent). These concepts were words and phrases that described some aspect of the lived experiences of caregivers and HBCW (such as powerlessness, role overload, role conflict). Concepts describing complex phenomena were subdivided into sub themes.

With an exhaustive amount of ‘meaning’ themes and sub-themes, I developed a coding framework in NUD-IST. All transcribed unstructured interviews were imported into NUD-IST as text files, and the coding process began. The themes and sub-themes became the nodes in NUD-IST. I then went through each transcript, selecting relevant text where the participant talked about issues related to each of the themes and/or sub-themes, and tagging it under that particular ‘code’ (theme). I then retrieved information on each particular node (theme), printed it out and wrote about it, searching for all possible meanings within each theme. Key demographic data (such as age, gender, geographical location—urban versus rural, and marital status) for each participant were also programmed into NUD-IST, so that when nodes were printed, this information would be on each excerpt or coded text. Knowing this information at a glance made analysis easier, especially comparison of text from different participants. However, for each theme, single-subject analysis of the ‘experience’ was done before inter-subject analysis, with the analysis of the role of the context in the process.

#### Ethnographic analysis:

[M]oves beyond description to reveal or explain aspects of social patterns or observed conduct...an interpretative science that searches for meaning within cultural norms, the culturally patterned behavior, and the cultural context...[C]omparison...reveals that the assumptions and rules regarding relationships are culturally bound and not universal (Morse & Field, 1995: 27).

Descriptive ethnography, therefore, will try to identify the social complexity that underlies the society (Morse & Field, 1995).

The major objective in this ethnographic analysis was to reveal culturally embedded norms that implicitly governing caregiving and support provision and receipt in a Zimbabwean culture. The same thorough reading of transcripts and field notes that helped to produce themes and sub-themes for phenomenological analysis also helped produce a set of themes and sub-themes pertaining to cultural issues. The themes and



sub-themes were developed into a framework in NUD-IST, where they became nodes. The key to a realistic and accurate description that provides an immediate feel to a qualitative study is the use of direct quotations from the informants (Creswell, 1998; Morse & Field, 1995). In order to do a good job of this I followed Creswell's (1998) suggestion, and created a 'quotes' node under each theme, where I coded good quotable text. These quotes were then used to make thick descriptions in the development of the ensuing interpretive and analytic work.

## Rigor

In any qualitative research rigor is required in order to guard against errors brought about by threats to validity and reliability (Morse & Field, 1995). In this regard, Lincoln & Guba proposed four general constructs/criteria useful for the evaluation of qualitative research in order to increase trustworthiness (cf. Morse & Field, 1995; Marshall & Rossman, 1995). These are: 1) truth value/credibility, 2) applicability/transferability, 3) consistency/dependability, and 4) neutrality/confirmability.

Lincoln & Guba used the term - *truth value/credibility* to stand for *internal validity*, which is used in positivist empirical research (Morse & Field, 1995)<sup>7</sup>, and "the goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described" (Marshall & Rossman, 1995: 143). In this study, credibility was cultivated in several ways. First of all, the experiences and perspectives of the participants were reported in depth, and as clearly as possible (Morse & Field, 1995), using the participants' own words, such that the inquiry couldn't help but be "credible to the constructors of the original multiple realities" (Lincoln & Guba, in Marshall & Rossman, 1995: 143). There was an in-depth exploration of the research problem, showing the complexities of the relationship between social support receipt and provision, the stigmatisation of HIV/AIDS, and the socio-cultural milieu. The study also attempted a holistic description of the context, the environmental factors, the processes and structures of social interaction, and experiences of caregivers of PWHA. And all these efforts were embedded with data from the natural setting and driven by a



combination of theoretical frameworks, giving the study its credibility. In Marshall & Rossman's (1995: 143) words, such an endeavour "cannot help but be valid".

The second construct proposed by Lincoln and Guba is applicability/transferability, which is "...used to determine whether the findings can be applied in other contexts or settings or with other groups" (Morse & Field, 1995: 143; Marshall & Rossman, 1995). In quantitative research, this applies to how a researcher handled the threats to external validity. The data collection methods and analysis procedures used in this study were guided by concepts tied into theoretical frameworks. A researcher can easily go back and follow the laid down procedures. External validity was also enhanced by synthesizing the results from other studies that have looked into issues of social support, caregiving, and social networks (but in western contexts), and then comparing and contrasting the results. According to Morse & Fields (1995), this approach also helps to develop mid-range theory.

The study's generalisability was also enhanced by the triangulation of multiple sources of data. Data source triangulation " involves using different kinds of information to investigate a given research question..." (Nutbeam, 1998: 38, Morse and Field, 1995; Carlson et al. 1995; Lambert et al., 1995; Marshall & Rossman, 1995; Hammersley & Atkinson, 1983).<sup>8</sup> The data derived from the sequential and concurrent use of observations and field notes, socio-demographic questionnaires, structured and unstructured interviews with caregivers and HBCWs were used to corroborate, elaborate, as well as illuminate the topic, thereby enhancing the validity, transferability, confidence, and confidence in research findings.<sup>9</sup> The use of ethnographic methods in the study also helped to increase the study's transferability. According to Hammersley & Atkinson, 1983: 24) "ethnography/naturalism "reduce[s the]...risk of ecological invalidity", [s]ince it investigates social processes in everyday settings rather than in those set up for the purposes of research, [thereby lessening the] danger that the findings will apply only to the research situation..."

The third construct used to evaluate the trustworthiness of a qualitative research is Consistency/dependability (Morse & Field, 1995; Marshall & Rossman, 1995). According to Morse & Field (1995: 144), the emphasis is on whether the findings would be consistent if the inquiry were replicated with the same subjects or in a similar



context." However, the principle of an instrument that produces the same measurement over time (i.e., reliability) in quantitative research does not apply to qualitative research that has multiple realities (Morse & Field, 1995). In this study, therefore, the in-depth analysis and description of the multiple realities of participants, emphasising the uniqueness of experiences through the use of participants' own words were attempted, in order to account for changes and variation in the phenomena under study. However, ethnographic methods of observation and analysis were followed in searching for patterns of caregiving and support provision and receipt within these multiple realities.

According to Fetterman (1989: 26), patterns of thought and behaviour are a form of ethnographic reliability.

The fourth and final criterion from Lincoln & Guba is *neutrality/confirmability* (Morse & Field, 1995; Marshall & Rossman, 1995), which captures the traditional concept of objectivity (Marshall & Rossman, 1995), which connotes "...freedom from bias in the research procedure and results" (Morse & Field, 1995: 144). In empirical research, objectivity is achieved through the rigor of methodology by which reliability and validity are established (Morse & Field, 1995). According to Morse & Field (1995: 144), however, trustworthiness in qualitative research is achieved "by prolonged contact with the informants or by using long periods of observation."

In this study bias in the research was minimised by a fairly prolonged contact with informants, which amounted to an average of 4 meetings with each urban participant and 3 meetings with each rural participant. During these visits observation was a continuous task; hence it can be noted as 'long periods of observation' in the sense documented by Morse & Field (1995). During this time period, a comprehensive understanding of caregivers' lived-through experiences was achieved. Also, the systematic application of research design, data gathering (especially careful and accurate observation), and systematic analysis procedures helped to present coherent, credible and internally consistent data that help confirm the general findings, which led to relevant implications and policy recommendations. According to Marshall & Rossman (1995: 145), rather than use objectivity as a criterion, "...the qualitative criterion is: Do the data help confirm the general findings and lead to the implications?"



Another technique that helped to increase the validity and neutrality of the study was researcher triangulation during the beginning phase. Researcher triangulation "... involves more than one researcher in data collection and analysis" (Nutbeam, 1998: 38). One research assistant, with an undergraduate Sociology degree was hired to conduct 4 unstructured and 4 semi-structured interviews, for interrater reliability purposes. This was worked out in such a way that no participant would have both unstructured and semi-structured interview conducted by a research assistant. This assistant also compiled field notes based on the interviews as well as general observations. The two of us would diligently go through each one's interview, comparing what each of us was getting, and jointly strategising how to improve on our questions and techniques.

Since the time Lincoln & Guba postulated their constructs for increasing trustworthiness in qualitative research in 1985 (cf. Morse & Field, 1995; Marshall & Rossman, 1995), more effort has been put into other strategies. One such strategy pertinent to this study is an *audit trail*, described by Rodgers & Cowles (in Morse & Field, 1995). This is basically a clear documentation of the researcher's decisions, choices, and insights in the form of field notes that are dated, in order to place interviews in context (Morse & Field, 1995).

A deliberate attempt was made in this study to compile field notes that are detailed, showing the date, location, and what transpired. This was my audit trail. This placed the interviews within context. As indicated throughout this chapter, any changes in methodological approach and the rationale (e.g., the focus of semi-structured interviews that changed at the start of the rural portion of the fieldwork; taking photographs), were also noted. Other important decisions, such as the decision to limit the number of contact with caregiver participants from five to four, to change from purposive to snowball sampling procedures, were also clearly stated, backed by the rationale for doing so. This audit trail, coupled with the data sources triangulation reported above; are the two strategies Leininger (cited in Morse & Field, 1995) proposes to counter threats to credibility.



## **Ethical Issues**

### Ethical Review

This study obtained approval from the Health Research Ethics Board – Panel B of the Joint Committee of the University of Alberta, and Caritas Health Group in July 2000. It subsequently got approval from the Medical Research Council of Zimbabwe September 2000. The study was also endorsed by The Zimbabwe AIDS Network, which linked me up with the following institutions, whose directors approved it (Zimbabwe Red Cross Society, Mashambazou Palliative Centre, and Mother of Peace Orphanage). It also received endorsement and approval from the Ministry of Health & Child Welfare (Mashonaland Province) and the hospital administrators at Mutoko District Hospital.

### Informed Consent

To protect the rights of caregivers invited to participate, a process of informed consent was used. After being linked up with potential participants, I obtained written consent from all participants who agreed to participate. After introductions and information about the purpose of the study was read/explained, potential participants were assured that participation in the study was voluntary. They were also told that they could refuse to participate, and could withdraw from the study at any time/stage without consequences. Most importantly, they were notified that refusal to participate would not jeopardize their relationship with the institution (which supports them) that referred them to the researcher. None of the potential participants refused to participate.

After the participants showed interest in taking part in the study I told them I would be giving them a pair of household gloves, a disinfectant and ZW\$500 (CDN\$15) for participating in the study. This compensation was given because the prevailing economic hardships in Zimbabwe during that time were likely to make people (especially those that live on low incomes) refrain from devoting time to activities that do not generate income. Also, given that people with AIDS, as well as their caregivers might be reluctant to talk about AIDS because of the social stigma attached to it, incentives might help those inclined not to talk about these issues to change their minds. These incentives were also given to participants to thank them for the time that they agreed to devote to the



interviews. Before participants signed the consent form, they were informed that whether they completed the study or only one or two of the interviews, they would still be entitled to receive the promised compensation. However, owing to shortage of funds, because this was not a budgeted item, the rural sample received ZW\$200 (CDN\$6) per participant, plus the other two items.

Participants were also notified of the potential benefits of participation in the study. Also, participants were notified about the potential risks of agreeing to participate if they did not inform their significant others about their participation. Efforts were made to minimize those risks by making sure that they notified their spouses and other immediate relatives of their intention to participate. In other words, verbal consent was also sought from husbands and parents/parents-in-law.

In cases of married female potential participants, I requested to meet with the spouses or parents of potential caregivers to ensure they were informed. Potential participants were also notified that those affected by participation in the study would be referred to appropriate organizations/institutions for help if necessary. Anonymity and confidentiality issues were also explained to each participant. Consent was sought thereafter. Since a reasonable number of prospective participants were either illiterate or semi-illiterate, a decision was made to read information and consent forms to all participants (in their native language), in order to save time.

Since the study also used observational methods, mostly focusing on interactions between caregivers, home-based care workers, the AIDS patient and other immediate friends or relatives that visited, those persons who came into contact with the caregiver during observational visits were informed about the study and the purpose of the observations, and given a chance to refuse to have their words or actions recorded by the researcher. None of those informed refused to give this permission. However, although their interactions were observed, consent was not sought from persons who were regarded as peripheral to the main study, such as passers by, who only stopped by for a few minutes to check on the patient, and exchange greetings and other pleasantries. Although people are curious about strangers, it is culturally a sign of respect and politeness to say goodbyes quickly and move on. As a result, only family members that were found in the home were ever asked for consent. Morse & Field (1995) have warned



against an obsession with informed consent, which they say could end naturalistic research.

The procedure for recruiting community-based care workers was the same. In each case, participants were requested to sign the consent form before interviews began. Although all home-based workers were literate, they all preferred the researcher to read the information letter to them.

Contrary to my expectations before going out into the field, all caregivers and home-based workers were comfortable with signing the consent form. Since this is a traditional culture where verbal agreements predominate, and signing papers is likely to be treated with suspicion, my backup plan was to ask potential participants to have a recorded verbal consent. From illiterate participants I was content with participants drawing an 'X' in place of their signatures, a practice used in censuses and other quarters.

### Confidentiality and Anonymity

To protect the confidentiality and anonymity of findings, the following steps were taken:

1. All data was, and will continue to be held in confidence, and only the investigator will continue to have access to tapes and field notes/records. All participants were informed about this.
2. Any information that could link any piece of information to a participant was omitted in this write-up, and will be omitted from any other reports done in future. Hence a consistent coding system was maintained throughout the data collection exercise and write-up, such that the results only show aggregated group data and anonymous quotes.
3. Although names were used at the recruitment stage, these were never recorded or used in the field notes, interviews, or results. Participants were notified that this would be the case
4. No third parties were allowed to attend the interviews.



## Risks and Benefits

The interviews required a time commitment from respondents. Caregivers are busy persons, so interviews may be inconvenient in this regard. Therefore, at the time of asking for consent, prospective participants were also informed of the need to sacrifice some of their time.

The interviews also had the potential to raise hopes of immediate support in some caregivers, especially those in the low socio-economic stratum who might be in dire need of instrumental support. At the time of asking for consent, it was made clear to prospective respondents that the study was not a needs assessment so that help could be given to family carers, but a process that might help policy makers and organizations that support PWHA to make informed policies and decisions about support provision.

There was a possibility that the study procedures (particularly, conducting interviews in people's homes) might cause tensions in homes. This was most likely to happen where a spouse, parent or the patient might feel that the study was an intrusion into their private lives. Given that most of the caregivers were women, their subordinate position to men was likely to cause female caregivers to be victimized for inviting a 'stranger' into the home.

To avoid such eventualities, potential participants were asked to double check with family members before confirmation of recruitment. With most of the participants being women, efforts were made to interview them in a place visible to other family members, such that they can be sure nothing other than a conversation was going on. If not visible, a place close by (i.e. within ear shot, such as a nearby room/hut) was chosen, mindful of the need to keep the details of the conversation between the researcher and the participant. All significant others encountered, including husbands were comfortable with this arrangement during the required number of visits for the interviews.

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## Endnotes

1. Some of the ideas from the philosophy known as pragmatism that influenced symbolic interactionism are that: Humans define and do not respond; they believe what is useful to them; they see and define objects according to their use; and they can be understood primarily by focusing on what they do" (Charon, 1998: 30-31).

Charles Darwin's theory of evolution also influenced Mead's work and the direction that symbolic interactionism takes in studying the human being. Being a naturalist, Darwin advocated for the understanding of the world without recourse to supernatural explanation (Charon, 1998). Therefore Mead also argued that we should regard the human being in naturalistic terms, but went further than Darwin to assert that once humans learn a language and can reason, "the resulting being is able to turn on nature itself, actively controlling how the natural forces work" (Charon, 1998: 32).

Darwin's belief that the universe is dynamic rather than static also influenced Mead's work. With this influence, Mead came to see everything about humans as process, rather than stable and fixed. Thus:

Instead of the individual being a consistent, structured personality, the individual is a dynamic changing actor, never becoming anything, but always in the state of becoming, unfolding, acting. Instead of being socialized, the actor is always in the process of being socialized...[and] society is a developing process, characterized by ongoing continuous social interaction (Charon, 1998: 32)

The last influence on Mead was the school in psychology called behaviourism. Within this discipline Mead called himself a social behaviourist. According to Charon (1998: 33), Mead:

Taught that in human behavior there is an interpretation to be included, an understanding of the acts of others and one's own acts, and that as we observe human overt action we must always consider what is going on in terms of understanding, definition, interpretation, and meaning.

2. The first principle/idea concerns a "*focus on the nature of social interaction, the dynamic social activities taking place among persons*" (Charon, 1998: 27, emphasis in original).



The second one is the idea that “*...human action is caused not only by social interaction but also results from interaction within the individual*” (Charon, 1998: 27, emphasis in original). The third idea states, “*humans do not sense their environment directly but instead define their situation as they go along in their action...*” (Charon, 1989: 27, emphasis in original). The fourth idea is exactly this:

We are not controlled by what happened to us in the past; we are not simply playing out personality traits we developed early in our lives. Our actions are always caused by what happens in the past situation, more specifically, how we are defining what is happening there (Charon, 1998: 28, emphasis in original).

Therefore, the past plays a less significant role in causing what people do than the present.

The fifth and final idea is that “*humans, unlike other animals in nature, are able to take an active part in the cause of their own action*” (Charon, 1998: 28, emphasis in original).

3. Again, adherence to bureaucratic procedures forced me to see the district medical officer first, who in turn referred me to the district community nurse (DNO). Because she was not available, I had to see the assistant community nurse. I was notified that the district hospital no longer tested for HIV/AIDS, therefore they have no way of knowing who was or was not HIV positive. The former district AIDS coordinator, had since done a course in adult education, and was now working as a district health education officer. However, he was also not available to help with any possible connections he might be able to make. Unfortunately, my visit coincided with the week of the international AIDS DAY, and these cadres were chiefly involved in organizing this event.
4. The support groups that were overseen by this coordinator came from a geographical area with a radius of more than 10 kilometres. Home visits were restricted to patients in the surrounding vicinity only. Meetings of support group members would normally be carried out at the Mother of Peace Orphanage.



5. According to Morse and Field (1995), the application of probabilistic sampling procedures (e.g., random sampling) means that most participants chosen to participate may know nothing or little of the topic. In this case, random selection becomes useless to the aims of qualitative research, and it may also be a source of invalidity (Morse & Field, 1995). Therefore, "theoretical sampling dictates that the researcher knows who best to invite to participate, based on the theoretical needs of the study and the knowledge of the participant" (Morse & Field, 1995: 80).

A qualitative study that fails to meet the criteria of appropriateness and adequacy, therefore, produces thin results, and its reliability and validity are possibly threatened (Morse and Field, 1995: 80-81).

6. Speaking about triangulation in ethnographic work, Fetterman (1989: 91) states that:

Typically, the ethnographer compares information sources to test the quality of the information (and the person sharing it), to understand more completely the part an actor plays in the social drama, and ultimately to put the whole situation into perspective.

7. There is an assumption in empirical research that we can only measure one tangible reality (Morse & Field, 1995; Neutens & Rubinson, 1997), yet in qualitative research there are multiple realities the researcher has to contend with (Morse & Field, 1995; Wolcott, 1994; Swanson & Chapman, 1994; Creswell, 1994; Neutens & Rubinson, 1997).
8. According to Hammersley & Atkinson (1983), the use of multiple data sources avoids the risks that stem from reliance on a single kind of data: the possibility that one's findings are method dependent. Data-source triangulation also involves generally, the comparison of data relating to the same phenomenon but deriving from different phases of the fieldwork, as well as from different participants (Hammersley & Atkinson, 1983).
9. Marshall & Rossman (1995: 144) argue that the use of multiple cases, multiple informants, or more than one data gathering method can greatly strengthen a study's usefulness for other settings.

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## CHAPTER IV

### CONTEXTUAL FINDINGS

#### Overview

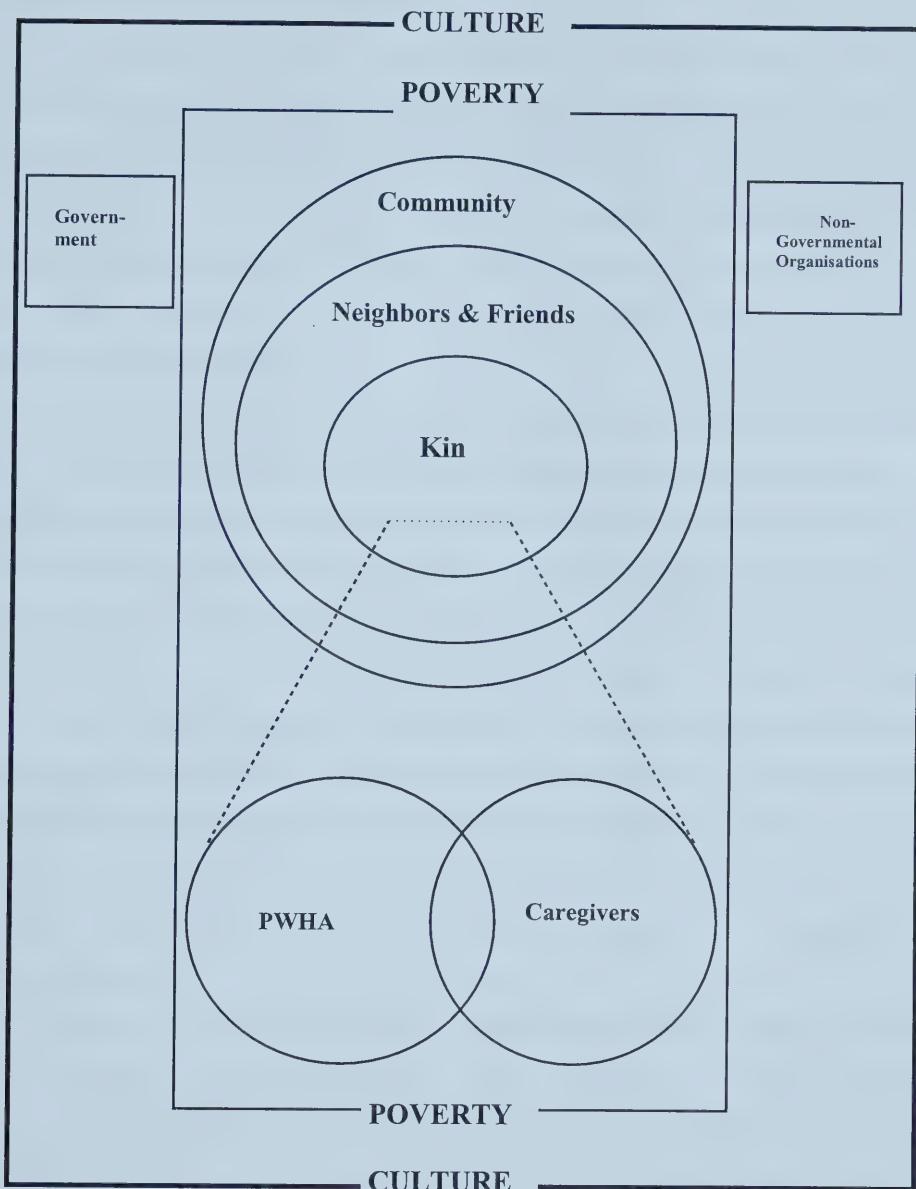
This chapter provides socio-cultural context, as well as some specific contexts (e.g. living arrangements) that fundamentally shape caregiving, support seeking and support receipt processes that are the subject of discussion in the next chapter. Laying out this socio-cultural topography allows me to analyse the phenomena that are the subject of this study, as they exist within their multiple social contexts, giving a holistic perspective of events. It is essential to describe these contexts, because the experiences of caregiving and social support are embedded in tradition, folk culture, social values and norms, and the social construction of knowledge. In order to provide these contextual findings, I have largely used data from the socio-demographic questionnaires, fieldnotes, photographs, my observations during the many times that I visited the participants, my earlier observations from a previous study in the District of Mutoko (Makwarimba, 1996), as well as my experiential knowledge as a *Shona*<sup>1</sup> person that grew up in that culture.

#### Meta Context: Cultural Realities

According to Hinds, Chaves, and Cypess (1992: 36), the omnipresent meta cultural context "...is a source of explanation for and an indirect influence on behaviours and events." It sets conditions for, and shapes the future. Culture shapes the motives, goals, attitudes, and thoughts of its carriers (Davis, 1992). As part of the meta context, cultural values and assumptions therefore guide behaviour (Morse, 1992). This cultural context is shown in *Figure 1* as indicated by the outer perimeter labelled 'Culture'. Social aspects of culture are important to describe, and include: (1) extended family and kinship ties and (2) the traditional health system.



**Figure 1: Contextual Elements Affecting Family Caregivers of PWHA**





## The Extended Family and Kinship Ties

Generalised reciprocity forms the first line of family food security in rural Zimbabwe. According to Mararike, "Collective coping strategies in villages, especially among family members, was and still is, an accepted form of survival," (1999: 95). Most villagers, therefore, rely on close kinship ties through the extended family, although strangers can be relied upon (Mararike, 1999). This is one of the principles of the *Shona* way of life. The basis for giving such assistance is that each villager would, in turn, require some form of help.

The emotionally close extended family kinship system, which is the dominant family organisation pattern in Zimbabwe, is the primary setting for guiding the acquisition of appropriate emotional display rules (Bourdillon, 1987; Nsamenang, 1992). Growing up in an extended family socialises one to have confidence that there are a number of persons who could provide social support (Bourdillon, 1987). In these extended families, provisions for one's support are supplied by a variety of persons. According to Bourdillon (1987), in urban areas of Zimbabwe, the extended family form has undergone some changes and has been altered and modified. Families were no longer residentially or economically intertwined like the extended families in the rural villages. However, the families interacted with one another frequently when distance permitted, exchanged assistance and services with considerable regularity, and maintained close emotional bonds.

High respect for elders and people in positions of authority are part of the traditions of the *Shona* tribe (Bourdillon, 1987). Generally, it is "believed that neglecting one's parents, particularly when they were old, would bring misfortunes upon oneself (Mararike, 1999: 94). This fear emanates from the belief that deceased kinsmen continued to take an interest in the behaviour of their living descendants, and therefore protected them, preventing evil, as well as helping them to solve their daily problems (Mararike, 1999; Chavunduka, 1978). This belief in one's ancestors was expected to act as a form of social security for the elderly because their children and grandchildren were obliged to look after them. "Fear of avenging spirits of wronged relatives or even strangers, acted as a regulating mechanism to people's behaviour towards other human beings" (Mararike, 1999: 94; Chavhunduka, 1978). It is Mararike's contention that, due



to this fear, the less fortunate members of society are not expected to be grossly neglected. Most importantly, traditional rituals, and collective worship and appeasement of ancestral spirits enable people to re-affirm their values and principles; it creates strong familial, lineage and clan loyalties.

### The Traditional Health System

Health knowledge does not exist in a vacuum; it is part of the social and cultural context of a particular society (Heller and Elliot, 1977; Helman, 1990; Igun, 1992). Values, attitudes, behaviour, beliefs and perceptions of health, health problems, health needs and illness are developed within these socio-religious, cultural and environmental foundations (Ngubane, 1977; Nyazema, 1984; Mutambirwa, 1985; 1989; Eudo, 1985). Because of these socio-cultural imperatives, indigenous Zimbabweans have their own health values, views on disease aetiology, transmission and treatment, which guide them to seek treatments as well as explanations for day-to-day life events from traditional healers.

On top of performing a purgative and cathartic function in order to reintegrate patients into their society traditional practitioners offer both social and mystical explanations for the causes of illness (Nyazema, 1984). Therefore, even amongst people who generally use western medicine when they are sick, there are instances when the illness is seen to have African experiential causes, and can therefore not be treated by allopathic medicine (Freeman and Motsei, 1992; Nyazema, 1984). Both traditional healers and their patients believe that illnesses are caused by many things; ranging from witchcraft and spirits to bacteria and germs. Hence traditional healers investigate all the environments (physical, social and spiritual) for the causes of diseases (Chavunduka, 1986; Mutambirwa, 1985).

Illnesses such as coughs, colds, slight fevers, headaches that occur from time to time and disappear are believed to be normal or natural (Chavunduka, 1978; 1986). The problems associated with physiological changes and those arising from ecological changes are of a fleeting nature and are accepted as natural processes of life (Chavunduka, 1986; Mutambirwa, 1989). These are illnesses that are believed to 'just happen'. According to Chavunduka (1986: 32), "many people agree that normal illnesses



are caused by such things as germs, bacteria, bad food, accidents and so on”.

Mutambirwa (1989) states that traditional belief is that ‘bad airs’, which are part of environmental air that contains good and bad elements, transmit these diseases. The first type is the bad air associated with diseases that affect the body and it is believed to originate from the physical environment. No spiritual significance is linked to them because their source is considered entirely natural.

Then there are illnesses that people regard as abnormal or unnatural (Chavunduka, 1986), or those caused by the second type of ‘bad air’, hence, also viewed as unnatural (Mutambirwa, 1989). According to traditional belief, if a headache or stomachache persists, or fails to respond to medication, the condition changes to abnormal or unnatural illness. Abnormal illnesses cause serious health problems that affect one’s physical, social and spiritual existence. The unnaturalness of the air emanates from the belief that the just Creator does not permit ills to attack his people. Hence such illnesses are thought to “originate from evil powers associated with physical or earthly aspects of life...” (Mutambirwa, 1989: 929).

Traditional beliefs do not preclude the ultimate authority of the Creator, but in between are the ancestral spirits through which people’s requests are channeled. Abnormal illnesses or ‘bad air’ that causes serious health problems are believed to attack those without spiritual protection from the ancestors and the Creator. Lack of protection from these powers lowers one’s resistance against the above health problems, and also causes bad luck in general. Ancestral spirits will not intercede for, or protect their posterity from illnesses or bad things if they engage in irresponsible behaviour, fail to observe traditional rites or fail to concede to some of their requests (Mutambirwa, 1989; Chavunduka, 1986).

The preceding suggests that in *Shona* culture, people's concept of health is inseparable from their concept of life. Humankind is believed to be made up of three parts; the body/flesh, the mind/soul (viewed as immortal, and continuing to function during and after death to become the ancestral spirit) and the spirit (which lives in eternal health through its moral and just function, and directs the body to carry out healthy physical activities by engaging in moral, just conduct (Mutambirwa, 1989: 928).



So basically there is no break of continuity between the world of the living and that of the dead.

All of the above conceptions then, determine (in part) people's decisions on where to seek treatment. In the case of normal illnesses, many people use herbs or go to modern medical practitioners or health centres, but once the illness is defined as abnormal, people usually "...consult traditional practitioners alone since they are aware that modern doctors are unable to attack the[ir] ultimate cause ..., namely, jealous neighbours and co-workers, spirits or malignant kinsmen" (Chavunduka, 1986: 32).

To the indigenous people, western treatments are for the body and traditional ones are for the body, mind and soul. Traditional ones heal as well as cure. Since official medical sectors are not organised to deal with these cultural meanings of health and psychological needs, people tend to accept, identify, seek and feel satisfied with indigenous health care because it is closer to them culturally and appeals to them emotionally.

In my earlier study (Makwarimba, 1996) in Mutoko District, I found that most people consulted the two medical systems in sequence, or at the same time. This is an indication that traditional medicine is still a viable and popular medical system in the country. Most importantly, traditional practitioners are available, accessible, affordable, acceptable, and culturally appropriate to the indigenous population (Chavunduka, 1986).

### Meta Context: Poverty

Poverty or deprivation played an extensive role in the lives of participants in this study. They were immersed in it; hence it conditions all aspects of their lives. It fundamentally affects their experiences of caregiving, as well as the processes of support receipt, support seeking, and support giving. Poverty is here conceptualised as more than income; a multidimensional concept, intertwined with all aspects of caregivers' lives (United Nations Development Programme – UNDP, 2000; WHO, 2000; Cohen, 2000).

Basic socio-demographic facts, living and caregiving arrangements described below are all indicative of the poverty and relative deprivation participants experience.<sup>2</sup> In this study all participants had low levels of education, few marketable skills and all but one (who had insecure employment) were unemployed. All but two participants had



meagre family assets, and the majority were bringing up their families in difficult circumstances, which include insecure housing tenures, and very low non-guaranteed incomes.

A UNDP (2000) Poverty Report on Zimbabwe indicates that overall poverty afflicts 61% of the population, and extreme poverty 45%, while The Daily News (2001, 5 April) states that as at October 2000, about 75% of Zimbabweans were classified as poor. However, a 2001 report states that 80% of the population lives below the poverty line (The Financial Gazette, 2001, 26 April, online edition). After averaging these figures, the percentage of poor Zimbabweans still remains at 72%, a very high figure indeed. In October 2000 the Employers' Confederation of Zimbabwe (ECZ), using the consumer price index (CPI) put the poverty datum line at a conservative level of ZW\$8,500, while the pro-workers Zimbabwe Congress of Trade Unions (ZCTU) argue that an average family of six now needs a minimum income of ZW\$14,000 or more a month, to subsist (The Daily News, 2001, Thursday, 5 April, online edition). Even if we were to use the conservative estimate of the ECZ (i.e. ZW\$8,500), the participant with the highest reported income of ZW\$5,200 comes ZW\$3,300 short of the poverty datum line. Therefore, with regard to both income and other socio-economic endowments, there is no question as to the extent of the poverty and deprivation experienced by caregivers.

This whole scenario that I am describing takes place within the inner rectangle of *Figure 1*, labelled 'Poverty'. This means, the whole community (of neighbours, friends, and relatives, etc), with the caregiver(s) and their patient(s) are immersed in the halo of poverty.

### Government and Non-governmental Organisations (NGOs)

Between the two perimeters marked 'Culture' and 'Poverty' in *Figure 1* there is a square labelled 'Government' on the left hand side, and one labelled 'NGOs' on the right. These are the major institutional players in the fight against AIDS in Zimbabwe.

The government established the National AIDS Coordination Program in the Ministry of Health and Child Welfare (MHCW) in the late 1980s, after realising the seriousness of the AIDS epidemic and the need for an effective national approach to the problem. However, by 1996 there was still a lack of an explicit Policy on AIDS



coordination (MHCW, 1996). Government efforts are mainly focused on STD control program, counselling services for PWHA, community home-based care, and AIDS awareness in general. In January 2000, the government instituted the AIDS levy on Pay As You Earn. A mandatory 3 percent has since been deducted from all workers every month and channelled into the National AIDS Trust Fund.

By July 1, 2001, ZW\$1,2 billion had been collected in the fund (Loewenson, 2001). However, by that date, only ZW\$120 million had been disbursed to one AIDS organisation. These funds, however, are meant for PWHA, particularly areas of HIV/AIDS needs, such as home-based care programmes, orphan care, medical care, HIV prevention and capacity building. To date, much of the funds have gone into funding income-generating projects initiated by support groups of PWHA, mainly in urban areas.

In my study, only one HIV+ participant indicated that her support group had received funds for an income-generating project. In Mutoko, PWHA were still organising themselves into support groups, as well as writing project proposals, in anticipation of funding by the beginning of 2001. However, past disbursement of the funds have been described as "erratic and inequitable" (Loewenson, 2001). None of the funds are meant for caregivers directly, and no government programme is focused on them either. So far, there is no national consensus on the key areas the nation should be targeting attention and resources to.

By 1996 the MHCW reported that there were about 60 NGOs involved in the HIV/AIDS/STDs prevention and care programme (MHCW, 1996). These organisations are mainly involved in conducting home care and supportive visits to affected families, and providing financial and material support including food supplements to affected families. Apart from these activities, one of the NGOs supporting PWHA and their families in the study also provides palliative care (i.e. Mashambanzou). Apart from having a palliative care unit, Mashambanzou has a self-help programme (for PWHA), day crèches, and offers home based care, orphan care and AIDS awareness education. Mashambanzou is registered as a Welfare Organisation that relies on donations from NGOs.

The Zimbabwe Red Cross, one of the organisations that facilitated this study has as its aim: "...to coordinate the provision of care for sick people either at home or in



hospital/ nursing homes" (Zimbabwe Red Cross Society mission statement). It focuses on sick people in general, including those PWHA. Workers also offer health education to caregivers. Although they give food supplements to poor sick people and their families, they do this at a much lower scale due to shortage of funds.

### **Local Context: The Rural and Urban Communities<sup>3</sup>**

I now move from the macro-context, to the more salient local contexts. The outer larger circle in *Figure 1* represents the two communities, urban and rural, that I will describe in this section. All the relationships and interactions between kin, neighbours, and strangers, take place in this local context, but are of course affected by the meta-contextual factors described earlier.

All rural family units to which the caregivers belonged depended mainly on farming for their livelihoods, including that of the only employed female caregiver. Each family's everyday life is normally dominated by a pragmatic concern to solve life-threatening problems such as food deficits, illnesses, and children's school fees.

In a rural village community in Zimbabwe, such as the ones rural participants were recruited from, interactions take place on a face-to-face level. Every person has fairly intimate knowledge about everyone else, their daily activities, their histories, their families, and their family histories. This is so because, for the most part, inhabitants of a village are more likely to be close or distant relatives than not. Although gradually falling out of fashion due to urbanization, rising level of education and other factors, customary dictates were more in favour of marrying someone whose parents were in good books with one's parents (*'Vematongo'*), or known to one's parents. This served as an assurance that one was marrying someone trustworthy; someone from a 'good' family. As a result, daughters and sons more often than not got married to someone living in the same village or one nearby.

In this patrilineal society, upon marriage, a son normally settles in the same village as his parents, more often than not building his homestead next to, or close to the parents'. All the rural participants had either their paternal or maternal relations living in the same village with them. Some had either of the two residing in another village close by. As a result, between each family unit there would be a network of kinships and



neighbourhood ties, which combine to place each person in a unique position in the web of relations between and among villagers. In this position, one belongs to a number of social units and/or organisations within the village as well as neighbouring or outside villages through marriage ties. Only two rural participants (however, these were a brother and a sister) had maternal relatives that lived very far (Zvimba District), in a different province. According to Mararike (1999: 50), marriage creates a bond between one's kin group and one's spouse, "...extending the network of people who could be called upon in times of distress."

Male and female spheres of activity are sharply divided, with women shouldering the traditional tasks of growing much of the food and caring for the sick and dying. Women and girls face the greatest burden of work in both rural and urban areas. Due to labour migration into the cities and other centres of employment, rural women and girls generally carry the greatest burden of work, given their customary responsibilities for agricultural production and raising a family, in the absence of their husbands that visit either weekly, monthly, or after a very long time, depending on transport costs and other considerations. For this reason, women head most rural households, and at times, remittances from male migrant workers are not dependable.

Due to a shortage of housing in urban areas, which forces most labour migrants to lodge a room or two, as well as lack of household tenure for most occupiers of municipal houses in the high-density low-income suburbs, most people have a great incentive to maintain a rural home. Some do so because they need a place to fall back on during old age, owing to lack of social security provisions that comes with most low paying jobs. In this case, after years of working in town, one seeks refuge, or social security from the soil (in agricultural production) because it is available, 'cheap' and 'dependable'. With others, it is a matter of maintaining their connections with their ancestry, so that they can be buried where their ancestors were buried. Therefore, most black Zimbabweans have a rural home and an urban home. The upshot is that there is an unbroken link between urban and rural life. Consequently, costs of HIV/AIDS are sharply borne by rural communities, as HIV-infected urban dwellers and labour migrants often return to their villages of origin when they fall ill. In this study, for example, four rural patients (out of eight) had returned to their rural homes.



Rural livelihoods depend much on natural resources (some of which are communal property) management and/or exploitation, and one's sheer resourcefulness and hard work. And, since about 98 percent of rural villages countrywide are not electrified, there are no electricity bills, and there is no rent to pay. Therefore, families use their incomes for buying food and other basic goods. This is one other reason why most people prefer living in the rural areas compared to urban areas, where one has to buy almost everything, including a bundle of vegetables, or a cob of maize. If one happens to be a lodger, like some of the participants, then the use of the small backyard garden might be reserved for the landlord. Where shacks or cottages have been erected behind the house, there might not even be a backyard garden. This is the kind of life that urban dwellers face.

Residential stands in high-density suburbs are very small, a vestige of the colonial legacy that has continued in the post-independence era. As a result, some houses are just a metre or a metre and a half apart, and some are semi-detached, with a one-brick wall in between. Therefore, compared to rural villages, privacy is very minimal.<sup>4</sup> For instance, one participant in the present study living in a semi-detached house indicated that sometimes her neighbour comments about the verbal fights that she has with her wayward son, and sometimes calls the son over for some kind of counselling, all on the basis of what the neighbour would have heard through the thin walls.

Unlike in the low-density suburbs, where family units are independent and self-sufficient, in high-density suburbs, just like in rural villages, every person has fairly intimate knowledge about everyone else, their daily activities, their histories, their families, and their family histories. Interactions also take place on a face-to-face level because of the closeness of the houses. However, the differences are that, in the urban areas, these are just neighbours, not relatives. Therefore, people tend to be more impersonal in their relationships. As a result, cordial interactions are more limited to friends and friendly neighbours.

### **The caregivers: Socio-demographic Characteristics**

From the community context described above, I now single out caregivers of PWHA, so that I can describe their attributes and circumstances. This will provide further



context for better understanding their caregiving experiences in the following chapter. The lower circle, labelled '*Caregiver*' in *Figure 1* represents these participants. Some information about their patients, such as duration of illness, relationship to caregiver, will also be provided. The circle labelled '*PWHA*', therefore, represents the patients. These two circles intersect, because of the dependent nature of patients on their caregivers, and the sometimes symbiotic relationship between the two. The two dotted lines on the outer sides of these two circles mean that I have 'pulled' out the caregiver and the patient from the community context. The reason for this will be explained in the next chapter.

Twenty-four family caregivers took part in this study. Fourteen of these were sampled from an urban (Harare) area, and 10 from a rural area (Mutoko). In this section, I will paint a descriptive portrait of the participants, their living as well as caregiving arrangements.

### Description of Participants

Sex. The total sample of 24 family caregivers comprised four males, making up 17 percent of the total. Three were from an urban setting and one was from a rural setting. The remaining 83 percent of participants (n=24) comprised of female family caregivers. The unavailability of male caregivers contributed to the preponderance of female caregivers in the study.

Age. Due to pre-study stipulations based on ethical concerns, all family caregivers included in the study were adults, except for one rural sixteen-year old boy who was interviewed together with his sister, a co-caregiver. According to Table 1, the mean age of caregivers is 35 (SD=12.7), and, there is a difference of four years between the mean ages of the urban and rural sub-samples, which are 38 (SD=10.99) and 34 (SD=15.2) respectively.

Diagram1 shows the age distribution of caregivers. It illustrates that the most number of caregivers (n = 15) are in the 20 – 39 age group, at 62.5 percent. On the other hand, there are only 4 (17 percent) older caregivers above the age of 49.

Diagram 1 also shows the aged distribution of the patients under the care of these family caregivers. The distributions are very similar. Literature points to the fact that AIDS affects (kills) people in the socially and economically productive group of 15 – 49



(Cohen, 2000; Mutetwa, 2001; United Nations Development Programme, 2000), and, this is the pattern reflected in the part of the diagram showing the patients. In matching the age distributions of both patients and caregivers, and showing the homogeneity in the two sub-samples, Table 1 shows that the age group of caregivers predominantly affected is similarly the productive age group.

**Table 1: Socio-demographic Characteristics of Family Caregivers (n=24)**

CHARACTERISTIC	TOTAL	SAMPLE	URBAN	SAMPLE <sup>#</sup>	RURAL	SAMPLE <sup>+</sup>
	Mean	SD	Mean	SD	Mean	SD
Age	35	12.7	38	10.99	34	15.2
Education (number of school years)	6.5	3.9	7	3.8	6	4.2
Number of children	3	2.7	4	2.8	3	2.6
Gross monthly income (in Zimbabwe \$)*	1,500	1,552	1,642	1,548	1,344	1,548
Number of family members depending on gross income	6	2.4	5.8	2.7	6.2	1.8

\* The exchange rate is CD\$1 = ZW\$35

# n = 14

+ n = 9, since one participant was a high school student

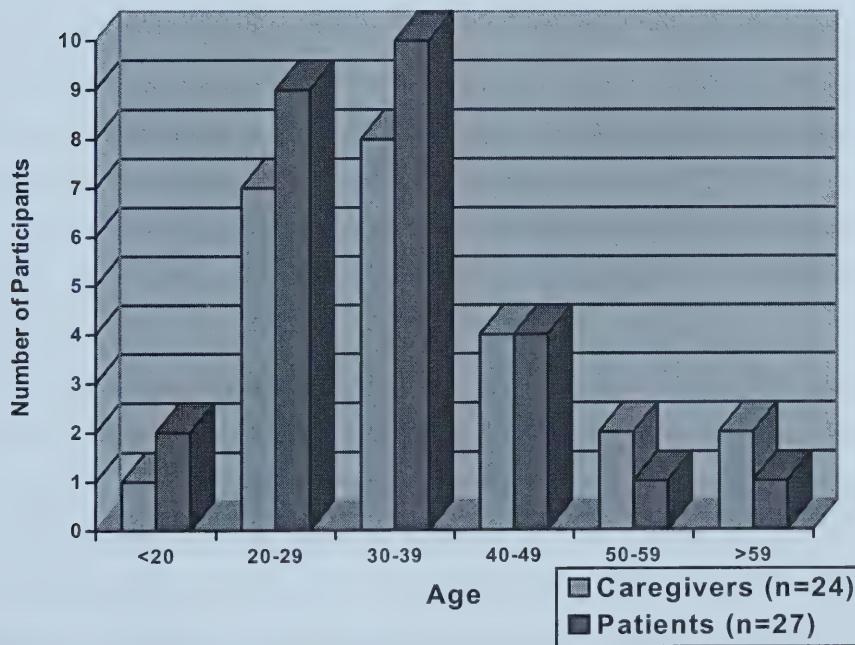
Marital Status. The majority of caregivers were married (n=13; 54%). Eight of these were urban, seven female, and one male. The next largest category was that of widowed participants. One of the widowed participants was urban (and male), while two were urban females, and the remaining two were rural females. There was only one separated female urban caregiver, and two divorced female caregivers, one rural and the other urban. Of the three single participants, two were male (one urban and one rural), and one was a rural female caregiver. One female caregiver was divorced by the husband she was caring for a few weeks after our second interview.



Number of Children. There are on average a relatively small number of children per caregiver in the sample; 9 caregivers (38%) have either none or one child, and the most number of participants (mode=6) have two children. The average number of children in the whole sample is 3 (SD=2.7), as shown in Table 1. The table also shows that the mean number of children for the rural sub-sample, at 4 (SD=2.8), is only one above the mean of the urban sub-sample (mean=3; SD=2.6).

There are only three participants with 7 children, and two participants with eight and nine children each. There is therefore, quite a wide range, of nine.

**Diagram 1: Age Distribution of Family Caregivers and Patients**



Education. In terms of years of education, there is a fair level of homogeneity in the two sub-samples urban and rural. Table 1 shows the mean years of education to be 7 (SD=3.8) for the urban sub-sample, and 6 years (SD=4.2) for the rural sub-sample. The mean age for the whole sample is 6.5 years (SD=3.9), which is below the seven years of primary school education necessary for entry into high/ secondary school. The mean is pulled down by four extreme low values in the 'no education' category. The median for the whole sample is therefore 7.5 years.



In total, there were eight participants (33%) that never reached grade seven, in contrast with seven participants (29%) that reached Form 4 or 'O' Level (equivalent to Grade 11), a high school-level exit into College or Polytechnic education, provided one has five or more passes, with a Grade C or better. None of the participants ever reached 'A' Level/ Form 6 (equivalent to Grade 13), which prepares for college and university education. Only one participant was still in school (Grade 8) at the time of the study.

All the participants that received no education ('none' category) were in the older age group (45 – 60+), of which one is male. One of these participants received two years of education. There are two possible reasons for this scenario. The first one is the overall pre-independence/ colonial educational policy that discouraged and had minimal resources allocated for African academic education, which was in effect up until 1980, when some of these participants were already in their late 20s. The second possible reason is the low priority given to the education of girl children in many quarters of the Zimbabwean society, particularly in the pre-independence era.

Nevertheless, the end results of low levels education are quite dramatic and influential. They affect skills acquisition, job choice, and income, to name but a few.

Employment Status and Occupation. Only two participants, both female and urban based, had some type of skills training. One had some training in pre-school education, as well as home-based care training, post 'O' Level graduation. Illness in the family, where she was looking after three siblings - with the fourth one having died three months before the research started – prevented her from ever looking for a job after completion of the course. The second female participant possessing skills training (also with 'O' Level education) completed some commercial courses while on the job, in order to enhance her clerical skills while working for a government department. However, at the time of the study she was retired, at 48, on medical grounds.

The only participant formally employed was a female, rural-based caregiver that worked in a Crèche (Pre-school) mornings, and as a housemaid afternoons. Due to her level of formal education (Grade 8), and lack of occupational skills training, she falls into the unskilled category.



Apart from the retired (female), male student, and fully employed female participant, the rest of the participants (n=21; 88%) were unemployed. That is, they were not part of the formal employment sector. Of these 21, only the three urban male participants had ever worked for a wage, two of them having brief, non-permanent stints on the unskilled labour market, and one having worked a long time as a cook in middle class homes. He was retrenched about six months before the study. This leaves us with 18 (75%) participants that never worked for a formal income/ wage. This scenario is not surprising, considering the fact that the national unemployment rate stood at 60% in April 2001 (The Financial Gazette, Thursday, 26 April, online edition). Due to poor performing economic climate, more than 400 companies shut down in 2000 alone, retrenching more than 10 000 workers (The Financial Gazette, Thursday, 26 April, online edition). Nonetheless, employment would generally be associated with steady incomes, stability and predictability.

*Housing, Household Amenities and Livelihood Resources*:- Due to the colonial policy of separate development, there existed two types of suburbs, high-density for Africans, and low-density suburbs for the minority Europeans. This dichotomous urbanisation strategy led to the development of low-density suburbs with large, beautiful houses on medium to large stands, amidst plush shopping and entertainment facilities; and high-density suburbs with much smaller, less attractive houses (sometimes back-to-back/semi-detached houses), on much smaller stands, and supported by poorer grocery shops. Homes in the low-density suburbs have always belonged to owner-occupiers (who may choose to sell at any time), whereas traditionally, homes in the high-density suburbs have been under the ownership of municipalities, to be rented out by occupiers.

After independence, Africans began to gain access into low-density suburbs, but due to the expensive nature of the up-market houses, this access has been limited to those with middle and high incomes. However, all high-density suburbs have a sprinkling of middle-income dwellers.

The urban sample in this study was selected from four different suburbs, all of them high-density suburbs. All the participants also happened to be in the low-income category. Out of the 14 urban participants (68% of total sample), only 4 participants were



residing in their own houses. Of these 4, only one participant had a house that had been extended to make it a fairly large and attractive family home with three bedrooms. Of the remaining three, one was living in the main house, in its original two-room structure as supplied by Chitungwiza Municipality, but had constructed a two-room cottage for rent in the yard. The remaining two resided in their own two-bedroom homes, but rented out one of the rooms to lodgers. Two other participants lived in family owned homes, not theirs per se. One other participant that owned a house was living in one room of a two-room cottage with the patient (son) behind the main house. A lodger was occupying the other room, while his wife and the rest of the family lived in the main house with other lodgers occupying other rooms. *Photograph 1* shows this caregiver in front of his cottage, with a toilet on the left hand side.



**Photograph 1: Cottage**

Whether one owns a house or it is family owned, all these participants do not yet actually own their homes. Prior to the early 1990s all municipal houses were only available for rent. They were the property of the municipality, and tenants did not have housing tenure. Since about five years ago, tenants can now pay rent, on a rent-to-buy basis, over a period of 25 years. Prior to this, the house belongs to the municipality, and tenants have no title deeds. Therefore, all the above participants who lived in their homes, did not actually own them.



Two of the urban sample participants lived in family owned shacks, while one lived in a family owned cottage, all situated behind the main houses. Of the remainder, four participants were renters, with two renting shacks behind main houses. One of these had four children; hence she, the sick husband and their four children resided in that one-room shack. The remaining two urban participants were renting a room each, in a main house. Of these two, one had a family of 5 siblings; all living in that single room, but the participant (male) would go and sleep at a friend's house. The other participant renting one single room had to accommodate a husband, two children and two other dependents, and their furniture in that single room. A standard room is about three meters squared.

The need to raise household incomes forces most urban low-income homeowners to construct structures, for the most part illegal, behind, or by the sides of main houses, to accommodate lodgers. A good example is depicted in Photographs 2 and 3. *Photograph 2* shows a caregiver standing in front of a family four-roomed home (with two of the rooms rented out); while *Photograph 3* shows what lies behind the house, a two-roomed cottage, and two shacks on the left hand side. These structures are both for rent as well as occupancy by family members. The size of the household was 13, excluding the lodgers/tenants.



Photograph 2 (Main House)

Photograph 3 (Outbuildings) →





Essentially, all but one urban families lived in overcrowded dwellings, either due to the size of the room/house, or the size of the household. Apart from congestion, most were poor dwellings, especially the shacks and cottages, which could be cold in winter, and are prone to letting dust in through cracks between wooden planks, corrugated iron or plastic sheets. During the rainy season, water can also get in. For example, during my second interview with one participant (see *Photograph 4*) there happened to be heavy showers, and rainwater flowed in easily from around the door area.



**Photograph 4: Shack**

The over crowdedness in most of these urban homes, plus the propensity of shacks to exposing occupants to the weather elements increases the risk of infection by respiratory diseases. The poignancy of this scenario becomes all the more salient in the light of the fact that about 70 percent of the HIV/AIDS patients were either being treated for tuberculosis (TB) or had just completed treatments. Poor housing is a major factor in causing illnesses such as TB, which is itself exacerbated by the HIV epidemic.

Rural homes were not very different from urban homes. In fact, all rural houses were better looking and more fit for human habitation than urban cottages and shacks, and inhabitants had more room per person than all urban homes. Also, most rural houses were roomier than some urban houses. A good example is the home depicted in Photographs 5 and 6. In *Photograph 5* there is (from left to right) a toilet, the traditional



granary and kitchen, both grass thatched, and *Photograph 6* shows the corrugated iron-roofed main house with three rooms. Another grass-thatched hut does not appear in the picture.



*Photographs 5*



*Photograph 6*

All rural participants had an asbestos-roofed main house, with either two or three rooms, plus other rooms and/or huts around it. Therefore, regardless of the number of household members, there was no overcrowding in rural homes. However, 5 out of the 7 households had houses that lacked finishing touches (such as window panes, plastering, inside doors, and cement flooring) because of the impoverishment resulting from unemployment and devoting financial resources to caregiving. In three of these cases, the patient was the former breadwinner. Photographs 7, 8, 9 and 10 show some of these homes, where *Photographs 8 and 10* show the main houses as well as parts of one of three traditional grass-thatched huts in each case.

Family property in the homes was scanty for the most part. Among all urban participants, where there is electricity supply, only two participants had three plate stoves, a set of relatively good sofas, and a radio and other furniture. Their incomes were ZW\$4,000 and ZW\$5,200 respectively. The later had a TV and an extended, bigger house. The rest of the urban dwellers either cooked either on small paraffin stoves, one-plate stoves, or firewood (outside). Some households did not have a single chair or wooden bench to sit on. In most of these less endowed homes, the basics found were: a bed, bench, kitchen cupboard/unit, vegetable rack/trolley, and paraffin stove. Three urban homes did not have beds for the patient and other household members.





*Photographs 7 and 9* ↑

*Photographs 8 and 10* ↑

All rural participants cooked with firewood, in the kitchen hut. Three homes had radios, and four had sofas and chairs. Four rural patients slept on beds, while one slept on a sofa (in her parents' home), and three slept on the floor. The three that slept on the floor were once married (2 female and 1 male) and had come to receive care at their parents' (1 male and 1 female) or sister's (1 female) homes. Otherwise, the caregivers had beds themselves.

Rural dwellers normally have a slight edge over urban dwellers with regard to livelihood resources related to farming. Some of these resources are pieces of land for farming, which all participants had; as well as cattle and other domesticated animals, which most participants didn't have much of. Three participants did not have any cattle in their home, and have to depend on other people to plough for them. But one of these had four goats, while the other family had eight, and the other had none. The four that had cattle did not have many, the maximum being five cattle. This is of particular significance because, apart from being used as drought power; cattle are also an important asset in various social interactions such as marriages, family rituals and ceremonies, and



exchange in times of crises such as famine and major illnesses (such as AIDS). Therefore, cattle are "...always used as an indicator of one's social and economic status" (Mararike, 1999: 89). Some families only had few hens and roosters, with some having as little as 2 hens. Faced with an illness and impoverishment, the only way out sometimes is to sell some livestock in order to get some cash.

*Source(s) of Income*:- As stated above, there was only one rural participant gainfully employed in the total sample. According to Table 2, the largest number of participants (n=9; 39%) was engaged in different activities to raise income in the informal sector, ranging from selling vegetables by their gates or at the market, to selling home knitted and tailored articles/ garments. Among these were four participants that received start-up goods (biscuits, candy, popcorn, freezits) from Mashambanzou Palliative Centre for income generation.

The second largest category, as shown in Table 2, is that of participants that received relatively significant remittances fairly consistently from relatives, at 30.4% (n=7); followed by renting out rooms, either in the main house, or shacks and/or cottages built behind the main house, at 26% (n=26.1). Renting out rooms to lodgers is a source of income only available to urban or rural centre dwellers. In this case, the villages from which participants were drawn were far from Mutoko rural centre, where this might have been a viable option to homeowners.

While one urban female participant had retired on health reasons, and was receiving pension; the second urban participant benefiting from pension funds, as shown in Table 2, was a female participant looking after a sister. It was this patient's late husband's pension the family was subsisting on. The third urban female participant depending on pension income was receiving her late husband's pension benefits. The same participant indicated that she was receiving cash (ZW\$200) once a month from an NGO that supports people with AIDS.

Two urban participants indicated that they had access to some municipal land that they use for farming activities. However, only one participant produced significantly enough to make some income from her produce, depending on the adequacy of the rains, as well as her ability to buy fertilizers for her crops. Knitting and selling doilies, and



farming are her sources of income, and **Photograph 11** shows the participant standing in the middle of one of her fields, about 150 metres from her yard. As can be seen from the photograph, the older crop of maize on the left hand side was not fairing very well, compared to the new crop on the right that had been fertilized.



**Photograph 11: Corn field**

Although all rural participants do engage in agricultural activities almost full time during the growing season, Table 2 shows that only two families produced enough to obtain any surplus for sale, as well as exchange for other goods. The rest of the rural families were not able to get such surpluses. However, some of the little they harvested could once in a while be exchanged for other goods and/ or services, during crisis times, only to be faced with times of food shortages only earlier than would have been the case if they hadn't sold anything.

Five participants (21.7%; 3 urban and 2 rural) indicated that they often take on any odd job that comes their way for an income. In both the urban and rural areas this includes helping neighbours with chores for a charge. This category is closely related to that shown in Table 2 as 'seasonal labour'; which applies to rural areas where rural dwellers can either go and do piece work for a meagre wage on nearby commercial farms, or do piece work in the fields of other rural dwellers in exchange for money.



**Table 2: Sources of Income for Family Caregivers (n=23)**

Income Source <sup>i</sup>	Urban Participants No.	Rural Participants No.	Total	%
Employment	0	1	1	4.3
Pension	3	0	3	13.0
Farming	1	2 <sup>ii</sup>	3	13.0
Informal trading <sup>iii</sup>	9	0	9	39.1
Odd jobs	3	2	5	21.7
Husband's/wives job income	0	3	3	13.0
Seasonal labour (agricultural)	0	3	3	13.0
Rent	6	0	6	26.1
Remittance from Relatives	4	3	7	30.4
AIDS support organisation	1	0	1	4.3

<sup>i</sup>Sources are not mutually exclusive, hence some participants have more than one source.

<sup>ii</sup>Although all rural participants farmed, considered here were participants who made a surplus to sell or trade with other goods.

<sup>iii</sup> Included here are activities such as knitting and sewing, and selling of the products; as well as vending vegetables and other items.

Most participants were receiving income from more than one source, in order to subsist. For example, one participant on pension also depended on remittances from a sister, and former husband (now living in the United Kingdom, upon request, although infrequent), as well as from a lodger renting one bedroom inside the house. However, the lodger had moved out by the time the research ended, and more room was created for the patient, who had been living in South Africa. Another good example is that of a participant whose family was receiving money from lodgers in the main house as well as rooms in a cottage behind the house, as well as the occasional remittance from a cousin, the ZW\$200/ month that came from an NGO, and pension from her late husband's former employers.

It is participants that are able to use their ingenuity to mingle different sources that stand a better chance of raising an income enough to subsist. All the sources, with the exception of 'employment' and 'pension', are ephemeral and not guaranteed, such that for most participants the act of finding the next income is like a cat and mouse game. Rent from lodgers, although ordinarily not a stable source of income, the current housing shortage in Harare makes potential lodgers easily available, and can help bring in a relatively modest income.



*Gross Monthly Income*:- The gross monthly income helping to sustain the participant, the patient and the immediate family within the household, was for the most part, based on average estimates with the majority of participants. This was the case with most participants, except for participants that were receiving income from either pension, full-time employment, rent, and from an AIDS support organisation; that knew exactly how much was coming to them every month end. With the rest of the participants I had to work with them in order to list all the various possible sources (under the best of circumstances), and what they yielded. Hence, 7 (30.4%) participants, all of them with incomes below ZW\$650, qualified their answer with 'less than'. Only one participant earning more than ZW\$5,000 qualified her answer in this manner. A further 34.8% (n=8) of the participants qualified the agreed upon income with 'about' (i.e. +/-). The fact that participants could not say what their income was with certainty is a good indication of the precarious nature of their economic circumstances.

As indicated in Table 1, the mean income for the urban sub-sample (Z\$1,642; SD=ZW\$1,548) is ZW\$298 higher than the mean of the rural sub-sample (ZW\$1,344; SD=ZW\$1,548). The mean for the rural sub-sample is somehow propped up by two caregivers that otherwise live in Harare, but had come specifically for caregiving responsibilities. Their incomes of ZW\$5,000 and ZW\$1,000 are their husband's incomes. The mean income for the whole sample (ZW\$1,500; SD=ZW\$1,552) is almost halfway in between the means of the two sub-samples.

However, it seems that the three means (i.e., for the whole sample and sub-samples) are positively skewed by 7 values ranging from ZW\$1,600 to ZW\$5,200. Otherwise, the majority of the participants (n=13; 56.5%) had a gross monthly income ranging between ZW\$200 and ZW\$650. This leaves only 3 participants earning ZW\$1,000, ZW\$1,050, and ZW\$1,500; still below the sample mean. The median and modal incomes of ZW\$600 and ZW\$500 respectively, are therefore, more telling.

At the exchange rate of CDN\$1 to ZW\$35, the participant with the lowest income of ZW\$200 earns CDN\$5.71. The participants earning the modal or median income of ZW\$600 earn CDN\$17.14, while the one whose husband earns the most, ZW\$5,000, would have CDN\$142.86. For each family, therefore, survival would depend on how



many mouths there are to feed, and how costly commodities are. This issue is discussed on the next page.

People Living on Gross Monthly Income:- Although the mean number of children per caregiver is relatively low for the whole sample (mean=3; SD=2.7), the mean number of family members living on that income is much higher (mean=6; SD=2.4), as indicated in Table 1. The means for the two sub-samples are not very different, with the urban mean being slightly lower (mean=5.8; SD=2.7) than the rural mean (mean=6.2; SD=1.8). Both the median and mode stand at 6, equivalent to the sample mean. The smallest number of people supported by an income is 2, and the largest is 13, which gives us a range of 11.

The large difference between the number of children one has, and the number of family members supported by one's income is a good indicator of the extent of extended family relationships. This is a cultural issue that will be discussed fully below, in the context of support receipt and support giving.

Costs:- Looking after a patient involves medical costs, above other day-to-day household expenses. The more members there are in a household, the more money is required to meet their needs.

Table 3 shows 13 basic consumer goods, most of them in their smallest units possible (e.g. bath soap, washing soap, vegetables, tea leaves, loaf of bread). Purchasing these items currently requires ZW\$785.85, which is well above what 13 (56.5%) of the participants in the study earn per month. Noteworthy is also the fact that a basketful of these items would not last a fortnight for an average household of six. If this family of six should require two loaves of bread per day, they would need to have ZW\$1,800 per month for bread alone.

For a family to have a day's economy breakfast using items from Table 3; consisting of sugar, bread, tea leaves, margarine, and milk; they would have to pay ZW\$206 for these items. The last column in Table 3 shows the percentage increase in the prices of these basic commodities since January 2000. Which means filling up a basket will keep getting increasingly difficult as the cost of living continues to escalate.



Apart from food, caregivers need money for drugs to treat HIV-related (e.g. tuberculosis and blood cancer) and other opportunistic illnesses. Ideally, to deal with the AIDS virus itself, one would need anti-retroviral drugs (such as COMPIVAR and 3TC), which at present are costing between ZW\$50,000 - ZW\$60,000 per treatment (The Daily News, Monday 4, June 2001, online edition). These drugs would be beyond the reach of all the participants in this study.

**Table 3: A Basket of Basic Food Commodities (in ZW\$)**

COMMODITY	QUANTITY	PRICE (ZW\$; JUNE, 01)	CHANGE SINCE JAN. 00 (%)
Sugar	1 kg	27.60	75
Cooking oil	750 ml	60.50	33.8
Mealie (corn)-meal	10 kg	185.00	47.7
Bread	Loaf	30.00	75
Meat (beef)	1 kg	130.00	49.9
Tomatoes	1 kg	82.60	337.7
Tea Leaves	250 g	47.90	76.7
Margarine	1 kg	84.00	56
Milk	500 ml	18.10	58.3
Vegetables	Bundle Rape	17.80	182.35
Bath Soap	Tablet	29.50	72
Washing Soap	Bar	35.80	42.7
Petroleum Jelly	200 g	37.05	135
<b>TOTAL</b>		<b>785.85</b>	

\* Obtained from *The Financial Gazette* (Zimbabwe), "Fingaz Food Price Monitor", Thursday, 7, June 2001, (online edition)

\* The exchange rate is CD\$1 = ZW\$35

An average Day for a Caregiver:- What an average day has in store for a caregiver will depend on two key important things. The first one is the condition of the patient. A caregiver with an ill but mobile patient has more time to do other things in their life, including activities away from home, from time to time; compared to a caregiver looking after a seriously ill patient confined to bed. A caregiver looking after a terminally ill patient is even more restricted in terms of the scope of other activities they could do apart from activities directly related to caregiving. The second important factor concerns the nature of income generating activities they have to be engaged in to meet the basic family needs.



On average, in order of frequency, a caregiver's day consists of:

- cooking for the patient and other family members, and feeding the patient
- bathing the patient
- washing the patient's clothes and/or blankets
- toileting
- income generating activity
- sitting with the patient

However, for rural participants, whose livelihood depends mostly on farming activities, farming comes second only to the top priority tasks performed for the welfare of the patient, depending on the severity of the illness.

### Caregiving Arrangements

Caregiver: Patient Ratio:- The total number of patients with HIV/AIDS that were being looked after by caregivers was 27. Among all cases there were only four (two urban and two rural) clear cases of 100 percent caregiving by one primary caregiver. However, in the rest of the cases, I looked for the primary caregiver in the sense that they did most of the caregiving tasks, as well as being in charge of the overall welfare of the patient.

Only in one rural case did I interview three caregivers, because two of them seemed to share in the tasks equally well, and the third was interviewed initially, in the absence of the elder sister who had been caring for the father longer. Overall, however, the majority (n=15; 62.5%) were in a 1: 1 ratio with their patients. Five (1 rural and 4 urban) caregivers were in a 1: 2 ratio with patients, while one urban caregiver was looking after three (1:3) patients, with the fourth having died 4 months prior to the study.

Caregiver-patient relationship:- The most number of patients (n=9) were being looked after by a parent (5 male and 4 female), whereas, only two patients were being looked after by their children. The next largest category (n=8) is that of siblings taking care of either a sister(s) (n=6) or a brother (n=2). There were four female participants looking after their husbands, compared to no husbands looking after their wives. Only two patients were being cared for by other relatives; one by an aunt (mother's sister), and



the other by a grandmother (mother's mother). Overall, most of the patients were being looked after by a close relative.

*Duration of patient's illness*:- Ascertaining the duration of illness was difficult, largely because some of the patients' illnesses started while they were either away at their marital homes (before the in-laws decided to send them back to their family homes), or away working in Harare. In most of the instances where participants couldn't remember specifically when the illness started, I asked for the time when they got seriously ill enough to seek medical attention.

According to Table 4, the mean duration of illness was 28 months (SD=32.6). The mean was positively skewed by a couple of durations (n=6) ranging from 4 to 12 years. Otherwise most of the patients (n=15; 56%) had durations below the sample mean.

The duration caregivers had been caring for the patient(s) was also very variable, ranging from 2 weeks to five years, and 7 caregivers (26%) having cared for the patient for only less than 6 months. However, the mean for the whole sample is 14.4 months (SD=15.5).

**Table 4: Duration of Illness and Caregiving**

DURATION/TIME	MEAN	SD
Duration of illness in months (n=22)	28	32.6
Period caring for patient in months (n=23)	14.4	15.5
Daily time taken in routine patient care in hours (n=12)	6.1	4.5

Determining the amounts of time caregivers are engaged in caregiving related tasks were also quite difficult. Participants were asked how much time in hours they spent doing caregiving tasks on a typical day when the patient was seriously ill and confined to bed. A number of factors might have contributed to the difficulty. One of the problems was recalling how many hours they spent doing caregiving tasks two or more months prior to the interview, that is, when the patient might have got seriously ill. The



other problem might have been the difficulty conceptualising what they did almost routinely in hours, particularly for those with low educational levels. Because of these problems, only 12 participants supplied the required answer. With some participants this was achieved by going through every typical activity they did, adding up the minutes and hours.

The time taken to care for a patient varied from 3 hours to 20 hours, giving us a range of 17 hours. However, according to Table 4, the mean time taken in routine patient care per day is 6.1 hours (SD=4.5). The sample mean was slightly skewed by the 20 hours, because the mode and median are 6 hours and 5 hours respectively.

### Geographical Access to Health Services

All urban participants were fairly close to either a hospital or health centre, with some as close as five-minutes walk away from a health facility. Given the ready availability of public transport (commuter taxis) in Harare and Chitungwiza, those with money for transport can reach a health facility in a matter of minutes. However, without money for transport, as was the case with most urban participants, one has to be prepared to walk with the patient for between ten minutes to forty minutes.

The situation is different for rural participants in this study. The three different villages from which participants were recruited were 5, 10 and 11 kilometres away from Mutoko District Hospital, which is their nearest health facility. Apart from distance, some of the villages are located in areas not serviced by road networks, and hence are inaccessible by cars.

For one participant that lives 11 kilometres from Mutoko District Hospital, but fairly close (about 800 metres away) to a bus route, "... it takes about one to one and a half hours to get to the bus stop...[with] several rest stops..." because she has to push her sick husband in a wheelbarrow "... from home to the bus stop." Another participant that lives about a kilometre and a half from a bus route said, "When we get off at the bus stop we have to carry her [i.e. mother] on the back..." **Photograph 12** shows the path from the main road, and the mountain at whose base their home is situated. **Photograph 13** shows the river and valley that lie between their home and the bus stop.





**Photograph 12**

**Photograph 13**

When the caregiver and her patient were living in Harare, they visited one of the central hospitals "Up to ten times", to seek medical attention. Then they came to their rural home in August, and, by December they had visited Mutoko Hospital only "...three times." Accessibility was cited as one of the reasons for less regular visits to the hospital.

Four rural participants were recruited from a village about six kilometres from Mutoko centre, where the hospital is located. However, a very rough dirt road from the highway to Mozambique only goes halfway. Driving a small car, I had to go at ten kilometres an hour to get to my key informant's house. From there we walked for about one and a half kilometres along narrow paths, through a forest and a rocky valley to get to the homes of the first three participants, situated in the middle of the valley (beyond the trees in the foreground) shown in **Photograph 14**. The alternative route, usable by lorry or 'four by four' truck is circuitous and would have taken us much longer. One of the participants from this village said that to get to Mutoko Hospital "the transport we use is the [ox-drawn] scotchcart, so it takes a lot of time...Up to 1hr 30 minutes." While the father was in Harare, the family had taken him to the hospital "...many times," after they brought him to their rural home they "...ha[d] taken him [to the hospital] once."





**Photograph 14**

### Conclusion

In this chapter I have tried to do two things. Firstly, I have described the backdrop against which the 'lifeworld' of caregivers will be pictured from here on. This backdrop is the culmination of the interplay between the culture that the participants are all part of, and the poverty that pervades their lives. This milieu, as I shall endeavour to show in the chapters five and six, conditions caring, support seeking, as well as support receipt discourse and actions of caregivers for PWHA. Secondly, I have provided the essential socio-demographic characteristics of caregivers and their living arrangements. These, as well, should help us to understand why, and how caregivers experience their 'lifeworld'. In the next chapter I am going to explore the cumulative experiences of caregivers in the areas of caregiving, support seeking and support receipt.

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## Notes

1. The *Shona* people make up the majority (70%+/-) ethnic group in Zimbabwe. Although there are many different dialects, depending on which part of the country one comes from, all *Shona* speakers can communicate with each other with great understanding. The second ethnic group, *Ndebeles*, make up about 20 percent of the population.
2. According to Shaw, Dorling and Smith (1999) "poverty emphasizes lack of economic resources, and the term 'relative deprivation' stresses the conditions of living."
3. Some specifics regarding the particular communities from which participants were sampled have already been detailed in Chapter 3.
4. However, in the rural areas, depending on the availability of land in that area, a family can have a stand of up to an acre or more. Each family cultivates the immediate area around the houses, what they call '*paStand*', before they cultivate any other fields. However, with time, if there happens to be scarcity of land, parents parcel out part of the '*stand*' for newly married sons to build their own homes.

This arrangement was observed in one family where a son that had been living in Harare was the patient. He had come with his wife to stay in their home village, and he was given a piece of land just behind the parents house, and adjacent to his brother's.

However, all the participants' family stands in this study happened to be Fairly large, such that to be able to talk to a neighbour one had to shout out loud.

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## CHAPTER V

### THE LIFEWORLD OF CAREGIVERS: ETHNOGRAPHIC AND PHENOMENOLOGICAL ANALYSES

#### Introduction

Having provided the broader social and cultural milieu in which caregivers and their patients are situated, I will now proceed to flesh out that skeleton by providing the interactions that take place in those contexts. These are interactions and discourse on caregiving, support seeking, support-receipt, and reactions to HIV/AIDS and caregiving. In this process, I will work towards completing the puzzle created in the last chapter, in the form of *Figure 1*, whose parts I will interconnect step by step.

In this chapter I will present the ethnography of the interactions and processes mentioned above, as well as the phenomenological aspects, with the former providing the context for the latter. This chapter is therefore partly ethnographic to the extent that the caregivers who provide the focus for it are seen as interacting members of their cultural community;<sup>1</sup> and is partly phenomenological to the extent that it attempts to present empirical matters from the perspective of those studied (Cresswell, 1998), by bringing in the voices of the participants in the study. Ethnography was used with participants who were separated geographically (i.e. rural and urban), but had two things in common. They share a common culture as Zimbabweans, as well as share the experience of caring for PWHA. These provide the basis that allows for the synthesis of the data.

Taped interviews of the 23 caregivers and 5 HBCW were transcribed, analysed for themes that emerged as common to all participants' descriptions. After a coding framework was developed (Appendix G) in NUDIST, using those themes and sub-themes (categories or nodes), and the transcriptions were imported into the programme, the coding process comprised extracting significant statements from those transcriptions and placing them into the themes. Field notes were also incorporated into the themes, and, these themes became the raw data for analysis. The data in these themes were further organised into clusters of themes, which formed the backbone of the major sections of this chapter.



The identification of “patterns” or themes is central to ethnographic writing (Cresswell, 1998). While it was also used to organise data for the phenomenological component, the perspective of participants was brought to the fore through the use of analytic claims, short, eye-catching quotations, embedded quotes, longer quotations, and dialogue.<sup>2</sup> At the end of each quotation I put 'p' to stand for participant, and the participant's number in the study. I also used network analysis in order to shed more light on relationships between caregivers and support providers. Exhaustive descriptions of the ethnography and phenomena were therefore achieved through the integration of the results of the analysis.

## Caregivers

### Who can be a caregiver?

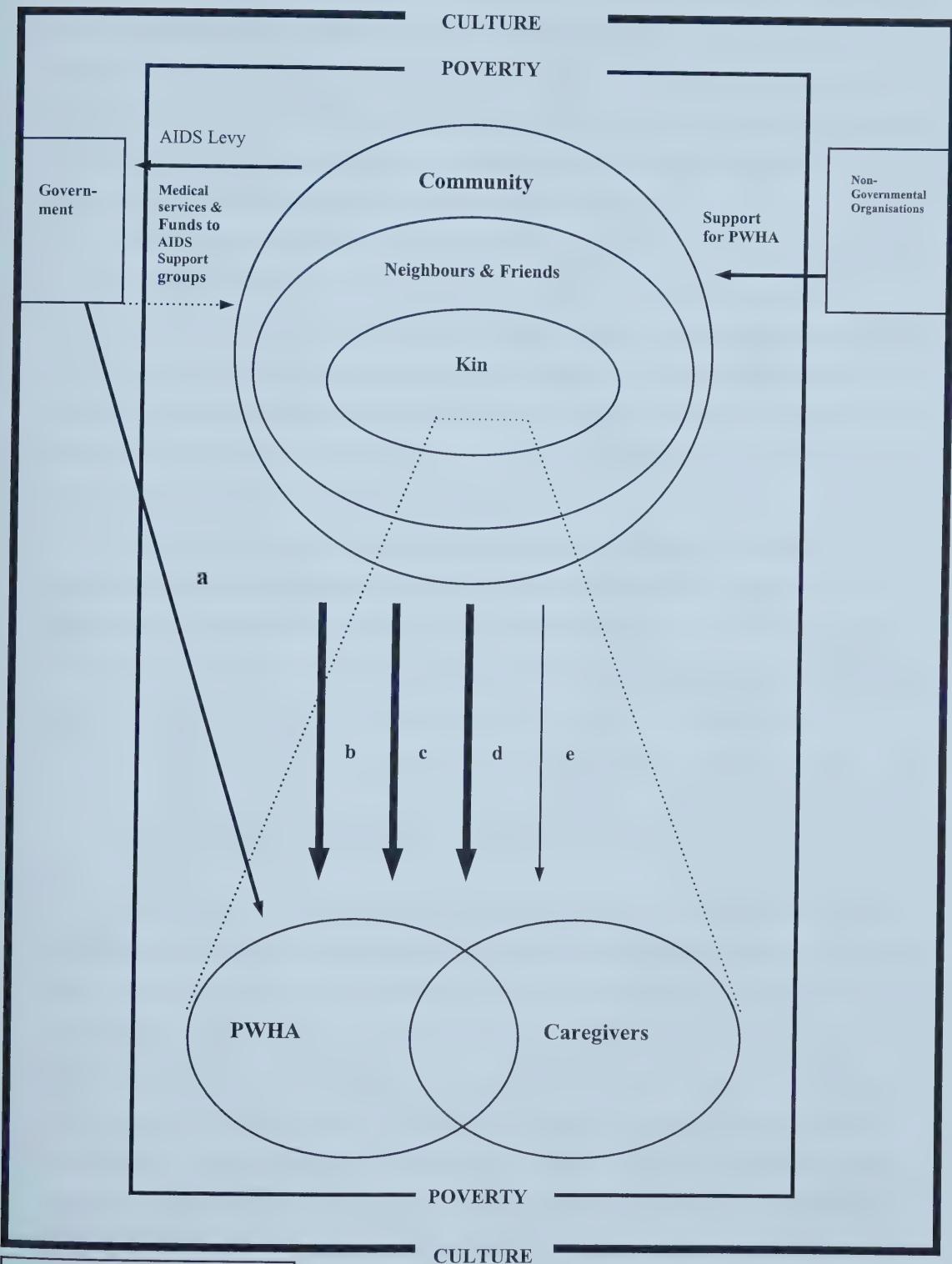
#### Gender dimensions

The nature of the study itself, which focuses on *family* caregivers, confines my search to the inner circle within *Figure 2*, labelled 'Kin'. The question we have to answer, therefore, is 'Who, among kinsmen can be a caregiver?' However, a few necessary preliminaries preclude my answering that question as yet. My participants were either male or female and, the preponderance of female caregivers in the sample (i.e. male: n=4; female: n=19) is one indication of the existence of a gendered customary role allocation mechanism. This role allocation starts with gender socialisation, as is aptly put across by this urban widower that was looking after a four-month-old baby:

*I am not happy with the care that I am giving [him] because I am a man. There is a difference in the way women do it...Being a man...most times I do not know whether the child has had enough food or not. Also, when it comes to doing other things, such as, ...when the child has just woken up – women know what to do. Even when he cries, I don't know what is wrong with him, whether he is hungry, or there is something else he wants...I also face problems when it comes to bathing him, I am not sure if I am doing the right thing; because these are things that women normally do, and we haven't learnt how to do them ourselves...If the child could get motherly care from a woman who can easily interpret the child's actions... (p. # 9-8)*



**Figure 2: Contextual Elements Affecting Family Caregivers of PWHA**



a: Early discharge of patients  
 b: Gossip & rumours  
 c: Loathing  
 d: Shunning & Ostracism  
 e: Social support



It is mostly due to lack of alternatives that such male caregivers continue to perform this function. The three other male caregivers, however, had duties such as cooking and washing of clothes performed by other female members of the household. Therefore, when a female member of the household is not a primary caregiver, chances are high that she becomes a co-primary caregiver or secondary caregiver, so that she can be responsible for tasks that are traditionally assigned to women.

This gendered role allocation is ostensibly accepted and reinforced by authority figures, perhaps inadvertently. When I spoke to an urban-based (volunteer) HBCW coordinator, she indicated that a home-based care/outreach nursing sister from one of my contact organisations is the one that "...talked to father... [i.e. the priest at the local Roman Catholic Church] regarding their desire for women to volunteer to get involved in looking after patients [in the community]." As such, all the HBCW from which I sampled were also female, in both urban and rural areas.

Socialised as such, women end up acquiring more caregiving skills and experiential knowledge compared to men, as perceived by the male caregiver I have quoted above. Women also believe they have better understanding of caregiving issues. For example, one of the female urban participants that had a brother that regularly helped her to transport her two patients (sister and mother) to the doctor/hospital said:

*Yes, he is one person I at least rely on. But you know, since he is a man, most times he doesn't get to really understand the depth of the illness. So, as a woman, I am the one to see to it that I change their clothes...And as you can see...all those tasks are problems that I have to deal with, (p. # 14-4).*

Although this caregiver perceived these many tasks as a problem for her, some caregivers that performed all the tasks on their own did not find this problematic, because these are responsibilities they have become accustomed to performing. Hence, on being asked about any possible stress-related problems the multiple jobs she was performing might have on her, one rural woman said that she was used to it, because "...this is not the first patient I have lived with...I lived with my mother last year, but she died, so I now feel that...it's not much of a burden anymore," (p. # 1-1). On being asked the same question, another female caregiver that had come from her rural home to look after her sister in Harare said, "...with regards to working, that's no problem because I am a hard worker. We do gardening, work in the fields, and other things, so sweeping in the house



is just a simple job," (p. # 12-2). Another urban-based caregiver that had spent much of her married life in the rural areas also said:

*I am used to it because we used to live in the rural areas, it's not a problem. Because being a woman you are always working...On your feet all day, you know that in rural areas there is quite a lot of work. For example, when you are ploughing, like during this time of the year, you never sit down. You have to prepare the fields and the seed, sweep the house, and do other things. All these things are jobs that have to be done, and once you get used, it becomes part of you. ['Kana zvajaira zvajaira']. Work ceases to be a problem, (p. # 13-3).*

Therefore, society confers responsibility for the performance of multiple roles, including caregiving, on women. Women then tend to internalise the roles and the attendant burdens with stoical endurance.

### Which family member then, can care for someone?

If women are generally accepted as caregivers, and men also take part in the caregiving process, but in limited numbers, who therefore cares for whom? For one thing, in *Shona* custom, a woman that marries into a family is not considered a close kin (*mutorwa*'), to the extent of being able to take long-term care for any other family members except her husband, children (or her siblings' children), and grandchildren.<sup>3</sup> It is not surprising, then, that I did not observe any daughter-in-law looking after a member of the family they married into.

Mothers seem the most natural candidates to take care of their children, but age, sex of the child, and the severity of the illness, also become important factors to consider; and, I shall come back to these shortly. Of the six female caregivers (three rural and three urban) looking after their children, four were looking after their daughters; with one looking after a daughter and a son, while two others were looking after their sons. This was the second largest category of caregivers. Married women also tend to become 'natural' caregivers to their husbands; and four (three urban and one rural) caregivers were playing this role.

While there were only two urban fathers looking after their sons,<sup>4</sup> there were five caregivers (two being co-primary caregivers for the same patient), all but one rural, that were looking after a parent. Siblings were the largest category of caregivers (n=7). Four



female caregivers were looking after same-sex siblings, while two were each looking after a sibling of the opposite sex, and one female participant was looking after a sister and two brothers, with the second sister having died three months prior to the study. In these caregiving relationships, the sex and age of either the caregiver or patient, as well as the severity of the illness also seemed to determine who become caregivers, as well as the need for a co-primary caregiver. These are issues that I would like to walk you through now.

*Deviant cases, and, who should care for whom, when?:-* According to the few caregivers involved, looking after a sibling of the opposite sex is deemed acceptable only when the illness is not severe. For the female caregiver looking after two brothers that were for the most part up and about, there was no burden or crisis, because they could bathe themselves. However, for a male and unemployed caregiver, his biggest wish was to "...get a job. I could then find someone to help her, and we would work together...[S]ince I am a man, I cannot get to the extent of giving her a bath, especially in the end [when she becomes bedridden]," (p. #1-7). This is a primary caregiver in the sense that he is the breadwinner, and cooks as well as washes clothes for the patient occasionally when she is confined to bed. Knowing the inevitable is just around the corner, the caregiver begins to realise his limitations as a caregiver for a sibling of the opposite sex.

However, for a sibling looking after a bedridden thirty-three year old brother who is in the end stages of the AIDS disease, the situation has already become desperate, as well as nightmarish. Her worry was that, "...since he is a man I cannot give him a bath." She went on to say, "You can see that he is filthy, and needs a bath, and I always agonise on what to do, or who will do it for me..."(p. # 3-4). The home-based care nursing sister from Mashambanzou had implored her to bathe him herself, and "...not to be ashamed because he is a brother." But according to the caregiver, "...seeing that he is male, and a brother, to me that is a non-starter. He also refused that himself", she said.

This tells me that shame is an emotion that affects both sister as caregiver, and brother as patient. The participant's solution to this was to "...just dip a towel into some water and give him to rub himself, because he can handle a towel at least...[and also] just



wipe his legs with [the] towel...with his trousers on,"(p. # 3-4). Feeling that she "...can't go and clean his body," and "...wouldn't clean around his genitals, [because] that is not proper for a woman to do," the caregiver had to ask a male next-door neighbour to come and assist with changing the patient's clothes.<sup>5</sup>

Mothers also have a hard time when it comes to caring for a bedridden son. The two urban participants that were looking after their sons were doing so under the best possible circumstances, because the patients could bath and eat on their own. They also did not need any assistance with toileting. Under such circumstances, a mother's affinity makes her one of the best candidates as a caregiver. However, there seems to be a re-definition of what is permissible or accepted when the patient becomes bedridden, or when the son has reached adulthood. The tasks she would have to perform then, just like the sister I have talked about above, place her in a position whereby she would have to play a deviant role.

One such mother, a rural sixty-on year old participant, a widow herself, that was looking after a divorced thirty-eight year old son that came to live with her (from Harare) because of the disease, found herself performing this unenviable role. Having no one to delegate the responsibility to, she said to me, "Yes, there is nothing I can do [since] it is my child that is sick." Her role, the tasks she had to perform, her predicament, and her motherly love were all expressed in these words:

*The problem with caring for a son is that it is difficult to change his clothes when he messes himself up. But when it comes to washing clothes and giving him food, there is no problem, because he is my child. You just handle him the way you used to when he was young. [In fact], he is now a baby; he has gone back to babyhood ('atodzokera kuhuhwana hudiki'). Just like the way I am handling him now, I put him on my lap, and feed him. So he has gone back to babyhood, and it doesn't frighten me anymore. What only frightens me is taking his pants off...(p. # 4-1).*

That is when she calls the patient's younger (married) brother "...to remove the soiled clothes and blankets..." so that she can go and wash them at the river. That motherly love that allows this participant to put her son on the lap to feed him, sharply contrasts with the standoffish approach of the sister I have discussed above, who had "...to pull him [i.e. brother] up to a sitting position, then place the food on his lap and he eats. [Then] ask him to place the plates on the chair by the bed after he has finished eating..." (p. # 3-4). Even when he asked for drinking water, she would "...place it beside his bed."



However, despite all that motherly love, this mother's resolve not to have to undress her son, or change his bed linen, is highlighted by the fact that, although she washes the soiled linen and clothes almost every morning before she goes to the fields, "If it so happens that he [i.e. younger son] has gone ploughing the fields early, I have to wait until he comes back," (Rural p. # 4-1). This caregiver's predicament is echoed by these words from a HBCW: "Myself as a mother, I can't bathe my own son...[I]t's not easy for one to bathe a son that you gave birth to, especially when they are older, you see" (Rural p. # HBCW5).

The converse situation is also true. Children of the opposite sex would not dare play the role of primary caregiver where it encompasses tasks that would entail undressing their parent. One female participant that had just come from her rural home to look after her sister aptly summed this up by saying, "...she has sons only, and it is not proper for a son to give his mother a bath" (p. # 12-2). This is the more reason why some patients end up with two primary caregivers. Two of the rural caregivers that were looking after their father, after the death of their mother three months earlier, were a brother and a sister. Their responsibilities were clear-cut, such that when a nephew that was helping the son lift and bathe the patient went AWOL, the bedridden father with bed sores went for more than a week without a bath, because the two elder sisters could not help him lift, undress and bathe the bedridden father, let alone change the soiled linen, a task that my informant and I did on our first visit.

Therefore, sex, gender roles, age (of both caregiver and patient), and the stage or severity of illness determine who becomes a caregiver. The severity of illness also determines the nature of caregiving tasks that need to be performed, as well as the 'caregiving rules'. Even after death, it is the appropriate persons designated by customary norms that would clean and dress the corpse. Therefore, given the normative rules discussed above that lead to the fear of being thought of as engaging in improper conduct, many caregivers would have to find a way out of such an impasse.

While, for example, society would frown upon a daughter bathing her father, and people might suspect an incestuous relationship between the two, doing so during such crucial times would not warrant any payment or compensation on the part of the daughter. Such a transgression of social norms would normally meet with censor from



other close relatives. The same would be true for a number of other relationships discussed above. However, the situation is completely different when it comes to a mother (for a son), or a daughter-in-law (for a father-in-law), because these two categories of women are regarded as outsiders. They have a different totem. Therefore, transgressing these social norms would meet with punitive sanctions from the woman's relatives, who would regard this as a sign of neglect and improper care for their daughter. In such cases, they would demand compensation, in the form of a cow, goat, or cash.

Caregiving tasks:- I found the caregiving tasks to be fairly varied. This depended on the stage of the patient's illness. Out of the twenty-seven patients, about eight were in the end stages of the AIDS disease, and were bedridden. They suffered from a wide range of ailments, including herpes zoster, diarrhoea, TB, bed sores, and complaints about most parts of their bodies. Unfortunately, five of them died during the last stages of the study. The rest of the patients were suffering from the whiplash of opportunistic illnesses, and were in bed on and off, depending on how soon the disease was combated. Most had TB and would also have diarrhoea now and then; some would break out in rashes once in a while, or develop herpes, among other ailments. But for the most part, they would be up and about.

The tasks that caregivers performed, therefore, could be placed on a continuum from light and intermittent, for the majority of the cases, to heavy/intense and continuous for a third of the cases. On the lighter and intermittent side, most patients could bathe themselves most of the time. Therefore, the energies of the caregiver were channelled into boiling bath water for them, and preparing food. For one such caregiver, "When she [i.e. mother] is seriously ill, we wake up early in the morning, and prepare thin porridge...[then] we warm water and give her a bath" (Rural p. # 5-1). However, "When she is better, she is able to wake up and bathe herself, and cook whatever she wants..." Similarly, another rural caregiver, a mother, said this about her daughter: "In the morning I warm up some water for her, then she bathes. Then I cook porridge for her...and sometimes when she is not able to, I give her a bath," (p. # 3-1).

Another caregiver looking after a sister (plus a mother with a stroke) said:

*Sometimes she comes and helps me to rinse those few plates...So, when she is up and about like this, I do not have much of a problem with*



*household chores most of the time. If there is something she wants to eat she volunteers to cook for herself [light, hearty laughter]. And that is quite a relief for me... these days, (Urban p. # 14-4).*

During such times, then, "Most of the time goes into seeing to it that each one of them has bathed in the morning...[and] I see to it that each one has eaten appropriate food."

At the extreme end of the continuum, however, some patients cannot even hold a cup of water or spoon to their mouth. A good example is that of an urban patient that could no longer talk by the time I started this study. Here is the chronology of day-to-day events/tasks the caregiver had to do:

*I first put water on the stove for her to bath; then I prepare porridge for her. Then I give her a bath. That will be about 7:00am... I [then] put clothes on her, and then feed her the porridge, and give her medication, if she has any. She likes fresh milk very much, so after a while I give her that, around 10:00am.*

*In the afternoon I change the diet and give her something like potatoes, or 'sadza' [thick porridge, staple food]. That's usually about 12 or 1:00pm, and then I give her medication again. Between lunch and supper I might give her a drink, [or] whatever she asks for, I try by all means to get it...She has sores all over her body, so I bathe her three times per day, so that the sores do not get worse....*

*In the evening I give her a clean nightdress because I am afraid they will get smelly, give her supper, give her tablets, then check her wounds and apply Betadine and G & I on them. Then we ...pray and go to bed. Yes, [she wakes up at night] when she needs her bedding and nightclothes to be changed. We are afraid if the bedding remains wet, her sores will get deeper. When she could speak for herself she would tell us when her bed was wet, and ask for a change. And we would change her all the time. [Sometimes we wake up] about three to four times per night...There are times when she has diarrhoea so much that she needs a change about eight times per night, to the extent that we would run out of fresh linen and night dresses (p. # 11-1).*

Who, honestly would have that much patience, and why? You might ask. Well, the answer lies in kinship bonds. All caregivers expressed the need to accomplish this obligation to their kin. The following excerpts are good examples:

*[One has to be] able to sacrifice to handle it [i.e. human waste] wearing gloves, in order to see that your relative is [okay] ... (Urban p. # 11-1).*



*Sometimes you feel repulsed by it all, but that is hard if the person fighting for life is your relative. ...If you are not a relative like that you ask yourself, 'What am I killing myself for?' (Urban p. # 12-2).*

*There is nothing I can do; it's my child that is sick (Rural p. # 4-1).*

*Since she is my mother, I see everything as easy. There is nothing problematic (Rural p. # 5-1).*

*In fact, when it is your child there is nothing you can say is a problem. No matter how heavy the load becomes, you have to carry it as a mother... (Urban p. # 5-6).*

*You can't 'throw away' your mother's child; you can't 'throw away' your relative. Since I am now his [i.e. brother] mother, whom can I 'throw' him off to? (Urban p. # 3-4).*

All these sentiments convey a sense of 'sacrifice', (as said in the first excerpt) or obligation to bear it all in order to help a close relative. We also get the sense that such a sacrifice would be hard to make for a stranger. There is also an implied redefinition of what under normal circumstances would be considered a problem, into something 'unproblematic'.

Caregivers also make other sacrifices, regarding where to do the caregiving. Four out of eight rural patients had been transferred from Harare, so that they could be cared for in their rural homes, and I have given the general reasons for this practice above. In both rural and urban sub-samples, there were a total of five female patients that came back to their families of descent, which partly says something about the perception that one will get better care from one's family of origin. I say partly, because in some instances the decision rests with the in-laws, who might decide to ask the daughter/sister-in-law to go back to her family of origin, especially in the case where the husband happens to have died first. I shall come to this issue in a later section. However, her decision to acquiesce and go back to her family of origin, speaks volumes about her belief that she will get the care she needs, regardless. I think the saying 'Blood is thicker than water' holds here. But the sacrifice I want to talk about here is with regard to caregivers who have to move out of their homes in order to look after a close kin in his or her own home.



The reasons for doing so are as varied as there are participants. Of importance here is the nature of the obligation or sacrifice to help a close relative. While others that take patients into their homes to care for them also make invaluable sacrifices, I think those that leave their homes behind make bigger sacrifices. For instance, a female caregiver said to me:

*Like right now, if I were someone [selfish] I would have just said, 'I can't leave my family alone to go and look after my sister and her children. ...I am seeing that many people end up taking the patient to live with them in their own home. Because it is tough to leave your own home to go and look after a patient...it is your home that suffers ('kwatobroka'). For example, in my case, this is November and the rains will be falling soon, and you would also want to prepare for the planting activities. And if you [are] ...not there during that time, you have failed for the whole year* (Urban p. # 12-2).

This caregiver had to put her farming livelihood, as well as her children's welfare on the line, to go to Harare to look after a sister. Two sisters made a similar sacrifice. One of them was a co-primary caregiver (with a younger brother), while the other was a secondary caregiver. Both left their husbands in Harare to go and look after their father in Mutoko. Being housewives, that was the time of year they would normally go to their husbands' rural homes to till the land, as is customary with women that have no formal occupation. One of the sisters said of their situation:

*Our husbands are supportive... (because of) the permission they give us to go to all the places we have been going [seeking medical treatments] with our parents... We know that families do have their rules...[set by husbands] but our husbands have never wanted to make things difficult for us or anything. That has been the trend from when we were looking after mother up until she passed away [three months before]* (Rural p. # 2-1F).

These caregivers had to travel long distances in order to go and look after a close relative. Some, however, do not have to travel that far, but the sacrifice is equally invaluable. One urban participant, whose unemployed husband had just been diagnosed with TB, had to go and look after a sister (and a mother who suffered a stroke) living a walking distance in the same suburb. Because of her dual roles, she said, "I have to play a balancing act, seeing to it that I don't abandon my marriage, as well as my relatives." Here is what she said to make me understand what she feels about her situation:



*I see to it that I wake up early, tidy up my place before coming here. But I have to be thankful that my husband is very understanding, because sometimes I wake up around 4:00 or 5:00am, and leave him still in bed. He understands the situation, because I asked him to understand. So he has to love me as well as understand what is going on inside and around me. If he doesn't see me when he wakes up he knows I have already gone [to the patients]. [laughter] ... If he did not understand, there is no way I would be doing this work (p. # 14-4).*

Here I have only looked at the sacrifices caregivers make in terms of deciding where they are to discharge of their caregiving duties, because it is directly related to 'who should provide the care?' This is so because one makes that sacrifice with the knowledge that he/she is probably the best possible candidate to perform the role among his/her kinfolk. Regardless of where the caregiving process takes place, there are, however, some generally agreed upon norms of looking after a patient.

### Rules of caregiving

'Rules' of caregiving are at best normative, and accumulate from interactional processes between lay people, as well as between lay and professional people. A visit to a health centre, doctor or hospital, traditional birth attendant, traditional medical practitioner; or a home visit by a professional (such as a nurse, environmental health worker) or semi-professional (such as HBCW) always has potential for the transmission of health messages regarding how to handle a patient. While it is difficult to discern the source of each norm or practice, I find this to be an important aspect of lay knowledge.

*The Dos:-* The helpless nature of a patient, particularly one that has a disabling ailment, or worse still, one that is bedridden, puts them at par with children in the type of attention they require. The caregiver that said, "...he is now a baby, he has gone back to babyhood..." (p. # 4-1), when talking about her thirty-eight year old son, summed up what I mean here. Generally, babies sleep with their parents, together, or on a separate bed until they are weaned. Depending on the occupation of the mother, some babies can be weaned at two years. This is a customary practice that has over the years been reinforced by health education messages about the importance of breastfeeding.

The majority of caregivers of the same sex as the patient slept in the same room with them. This was particularly the case with bedridden patients, or those that were



generally up and about, during the times they were feeling too sick to wake up to do things for themselves. This allows one to be immediately available should the patient needs help, or even to be able to make constant checks on the patient and ask if they need anything. For bedridden patients, it is also crucial that they be regularly turned to prevent bedsores developing.

Some caregivers that were married would put the patient in the next room so that they could check on them when necessary. A good example of the kind of attention I am talking about was shown in the case of an urban female caregiver looking after her sister; where the caregiver's presence was incremental, depending on the severity of the illness. When the patient's condition was better, their mother would sleep in the same room with the patient. "But when the condition was serious," she said, "I also sleep with them...and if it gets worse, my sisters come so that we can help each other," (Urban p. # 11-1).

The sex of the caregiver acts as a barrier to performing this essential function, in the same way it affects other essential caregiving tasks such as bathing the patient as I indicated above. One of the best examples is that of the sixty-one year old mother who said that when the son could still talk, "...he would say, 'Put my water container and cup besides the bed, I will get up and drink on my own.' Right now he can't do that; he just sleeps and never wakes up for water" (Rural p. # 4-1). Again, when he was still able to get up on his own, she used to put a bucket beside the bed, so that he could relieve himself at night; and she would empty it the following day, but at this point "...he [couldn't] get up. He just relieve[d] himself in the bed." Because the patient slept "...on his own, in the spare bedroom..." she couldn't do anything to help her son with drinking water or when he wanted to relieve himself. During the time that I visited for my study, the patient was completely helpless and incoherent. At one time I spent about fifteen minutes alone with him, and, during that time his head would roll off the pillow just soon after I placed it back. This is the kind of attention such a patient would need to have at night, but being a mother, she could not sleep in the same room with him in order to provide it.

There was an odd case though, of an urban female caregiver who would occasionally sleep in the same room with one of her patient brothers. Ordinarily, the brother slept in his own room (a shack), but he had the tendency to:



*[W]ake up during the night when he is in pain. Because he becomes so much afraid even to sleep alone in that room, ...he comes into my room... and he tells me 'we are sleeping together there'... and we sometimes sleep on the same bed (p. # 10-1)*

Such an arrangement is only tolerated in the spirit of caregiving, depending on the individual. Though a temporary or impromptu arrangement, it is definitely a deviant case.

Most caregivers also believe that a patient has to be given nutritious foods, as well as get pampered with their food choices. According to one caregiver, “Whatever she asks for, I try by all means to get it, in order to make her happy. That is how I do things” (Urban p. # 11-1). And another one said: “...then I ask what she wants to eat. She often prefers tea with milk, eggs, and her favourite buns, which I buy from the local shops; then they have their tea” (Urban p. # 14-4).

And some would say: “In between the morning and afternoon...we give him things such as bananas, oranges, soft drinks and other things,” or: “And you know that a patient needs good food, not substandard food, no,” or that, “because as a sick person, she needs better relish [not ‘sadza’ with vegetables].” Most caregivers prepared porridge for their patients, a food item mostly fed to children. Even in *Shona* custom, many traditional medicines are eaten with porridge made out of rapoko flour. Most caregivers would, therefore, prepare “thin porridge so that [the patient] can swallow it...” Sometimes patients refuse to eat anything, or certain types of foods; and the solution is to “...just go on persuading...” This means one is not supposed to give up on their patient, and, this leads us to the don’ts.

Don'ts:- According to one HBCW, a patient is supposed to be persuaded (‘murwere anofanirwa kunyengetedzwa’). If you do not have the food they want, “...tell them you will try your best to find it...But if you are harsh with them like this, their mind will continue to have high blood pressure, you see, ” (Rural HBCW4). She goes on to say: “When a person is sick, their brains transform, they are not like a normal person. You have to be patient and understanding. Whatever she does, just continue to use persuasion.”

Many caregivers echoed this sentiment, and one caregiver aptly stated this position by saying, “You know, when someone becomes a patient it is not proper to talk about things that might worsen their condition,” (Urban p. # 12-2). While many



caregivers concurred on the fact that patients are verbally abusive, it was the opinion of one of them that "...it is up to you to realise that you shouldn't answer a sick person back," (Rural p. # 8-1). While the majority of them said that they would take this lying back, or would turn the other cheek, one caregiver looking after an elder sister said, "...when you are a relative like this, you just wash it away; when she shouts at you, you can just shout back, and it ends there, you see," (Urban p. # 12-2).

However, not all caregivers would have this privilege in *Shona* society. One's ability to shout back would depend on the type of relationship between caregiver and patient, as well as the age of the caregiver. A child is not supposed to shout or swear at an adult; more so at a parent, because if one does, and the parent dies before one compensates them for that, the parent's spirit would come to haunt the child. Siblings can engage in that sort of fighting, but when the caregiver is much younger than the patient, again it becomes inappropriate to shout back. For example, the rural caregiver looking after a mother that I quoted above, said, "...it is up to you to realise that you shouldn't answer a sick person back," (p. # 8-1).

The ethnography that I have explored in this section provides the unwritten 'rules' of caregiving, processes that determine the interaction between caregiver and patient. This process then, its scope and dynamism, also determine the intersection in the Venn diagram (or circles) in *Figure 1*, labelled 'Caregivers' and 'PWHA'.

Having given the constraints and societal prescriptions I have discussed above, it is now opportune to explore the caregivers' experiences of caregiving. That is, how they feel about their whole involvement in the caregiving process. The focus, therefore, is centred on the right circle of the Venn diagram, which is labelled 'Caregiver'.

### **The caregiving *lifeworld*: How does it feel to care for a PWHA?**

The purpose of this section is to describe and interpret phenomenologically, the essence of the caregiving experience, or the lived experiences of caregivers of PWHA. Insights into the phenomenon of caregiving were gained using three main techniques: searching idiomatic phrases from participants' discourses, obtaining experiential descriptions from transcribed interviews (Morse and Field, 1996), and reflecting on the observations and field notes made during the course of the study. The caregivers'



*lifeworlds*, which I used to gain an understanding of the essence of the phenomena are multi-faceted, comprised of such key elements as: tending the patient (i.e. giving medications, dressing wounds, and assisting with toileting); securing foodstuff, cooking and feeding the patient; taking the patient to a hospital/ health centre; the psychosocial and physical effects of the preceding factors on the caregivers' health, and caregivers' reactions to the preceding issues and AIDS. All aspects of the discussion in this section are centred on the caregiver, represented in *Fig. 1* by the right circle of the Venn diagram, in some cases in direct interaction with the left circle that stands for the patient, particularly in the section on 'Caregiver Abuse'.

### Sickness: Tending the Patient

As I mentioned above, PWHA suffer from many different opportunistic illnesses. The caregivers' inability to afford antiretroviral drugs for their patients makes the HIV+ patients more susceptible to further infection(s). These illnesses present different symptoms and, one patient might suffer from two or more different opportunistic illnesses at the same time, or at different times. For the most part, this is a situation that brings *uncertainty* and *anxiety*, because there is no telling when the next bout will make its onslaught.

First of all, the fact that the patient has many complaints or problems one cannot deal with can be *overwhelming*. While these feelings of *uncertainty*, *anxiety*, and being *overwhelmed* by these recurring illness episodes were expressed by many participants, they were more aptly expressed by this rural female participant:

*[W]hen she has stomach problems [diarrhoea], what starts is severe itchiness in her vagina. It itches her and itches her, then she starts complaining about stomach problems....Then she complains of side pain and other things.... All happening at the same time. And the pain continues and continues.... [We] go to the hospital, and...she just gets tablets and comes back home, and it stops for a while. Then it starts again, and it goes on like that (p. # 7-1).*

The fact that this caregiver, at one point told her daughter that, "...if it's a disease that you were given by God, there is nothing I can do," also portrays a sense of *powerlessness*. It is something beyond her ability to help her daughter in a meaningful way. The *uncertainty*, and *powerlessness* discussed above tend to be protracted by the



fact that AIDS is an incurable terminal disease. This can lead to *despair* in both patient and caregiver. While this comes out in the words of the caregiver discussed above (p. # 7-1), where she leaves it to God, her daughter patient was also equally affected. According to the participant, "...what happens is that when we do not have money, and you talk of taking her to the hospital...she goes, 'Please don't bother ('hunzi regerayi henuy'), even if I go to the hospital the disease is not going away. And everyday you keep telling me hospital, hospital'," (Rural p. # 7-1).

Some of the caregivers are also *overwhelmed* in another sense, by the ghastly sores from the herpes zoster that is common among PWHA. Other symptoms also have an equal effect. For example, dealing with endless diarrhoea, which most PWHA suffer from, can be a nightmare for a caregiver. For example, the same female participant quoted above said, "When the pain starts, she can't even get up...and she asks me to prepare things so that she can pass stool on, you see. I might take a blanket or piece of cloth and push it underneath her. But sometimes she messes herself right there [before I do]" (p. # 7-1). According to another participant with a bedridden patient, "...there are times when she [patient] had diarrhoea so much that she would need a change [of clothes and linen] about eight times [per night]" (Urban p. # 11-1). This participant went on to say, "Doctor, human waste is not an easy thing to deal with... ('Chiremba, chinhu chinonzi tsvina chinhu chakaoma...')"

Apart from dealing with diarrhoea on a daily basis, caregivers also deal with sores and other unpleasant situations. One female urban participant that was looking after her sister and had to bathe her daily said:

*...[W]e put warm water in the tub ('bhavhu'), then add...[antiseptic, name not clear], written 'germ killer'. But these days she has been refusing it, saying it stings. Because the situation is that she has sores [from herpes] behind there [anus and genital area], ughh, it's really bad ('ughh, hazvisikuita'). The doctor said she has an infection there...hence she has to bathe twice a day....because she no longer has strength to bathe herself. So you put soap lather on the towel and clean those parts she wants cleaned, as if you are washing a baby.... After laying her on the bed, you apply some Vaseline on her body, then dress her sores with some medication. Sometimes you feel grossed by it all, but it's hard not to help if the person fighting for life is your relative ('...asi unombobatwa nekakusema asi aaa, zvinonetsa kana iri hama yako iri pakutambudzika kudaro') [p. # 12-2].*



There is a sense of *sacrifice* in this participant's words. Despite the fact that what she did was revolting, she felt she had an obligation to help her relative (sister). Another female urban participant that was looking after a husband and a brother described a similar situation. Apart from facing "...a real problem..." in the nature of not being able to bathe her brother, she also said, [not for the squeamish]:

*Moreover, he is letting out a very foul stench from his mouth, and I am always asking myself where it's coming from. These past few days, worms have been coming out of his mouth. Some are quite big, but sometimes there are small ones. It is really worrying me.... When I gave him the tablets [I was given] the situation became even worse, more and more of those worms were coming out. You could hear him say, "I can feel them in my mouth now," and he would spit them out.... and you could see them wriggling in the jug full of water, which I gave him for spitting into. You could see the worms going up the walls of the jug, trying to come out. I would wonder, "But where are these worms coming from?" And he would say, 'I don't know.' We don't know whether he had sores in the stomach or in his mouth, because he once had a tooth extracted, and he has a big hole where the tooth was removed. So we don't know whether they are coming from there or not. Those worms are gross, that type you see coming from rotten meat. That's what comes out of his mouth (p. # 3-4). [My emphasis]*

On my first visit to this participant's home, just a few days before the patient died, I went into the room to see how he was doing. The situation described here, plus the effect of bed sores, and the fact that the patient did not have proper or complete baths owing to the fact that she felt she couldn't bathe a brother, culminated into a reek that hit you right at the door. As a visitor, and researcher seeking the participant's cooperation, this was a trying moment for me. I had to retain my composure, talk to the patient before coming out. But it wasn't easy. It was a trying moment. This is perhaps the more reason the participant did not stay in the room to feed the patient, but "...pull[ed] him [i.e. brother] up to a sitting position, then place[d] the food on his lap [to]... eat.... [Then] ask him to place the plates on the chair by the bed after he has finished eating..." (p. # 3-4). But despite all this, there was that dedication and resolve to stick it out and help a relative that participant 12-2 and many other participants had.

Apart from feeding the patient, giving them a bath came out as another trying moment for most participants, especially for those looking after bedridden patients. One



gets a feeling of *helplessness* from most participants' accounts. A sixteen-year old rural participant said that:

*[T]here needs to be someone to hold him [father] onto the chair while the other one bathes him. Since I am alone these days, I cannot bathe as well as hold him at the same time. If there is no one to hold him, he will fall down, (p. # 2-1M).*

Therefore, despite the bedsores the father had, by the time of my visit, he had gone without a bath for more than a week. Similarly, an urban female participant said that:

*For sure, during the first days I used to bathe [name of patient] alone, but with the passage of time, realising that she was no longer able to sit, two or three of us would have to give her a bath, myself, my sister that lives in...[name of suburb], and the one that lives in...[name of suburb], (p. # 11-1)*

The progression of the disease, therefore, brought about a situation of *dependence* on other people to help with bathing in all instances where patients were bedridden.

According to the participant above, the patient "...had developed bed sores, so [she] used to bathe her three times per day, so that the sores would not get worse."

*Feeding the Patient: The Trying Times*:- Looking for food, preparing it, and feeding the patient present some of the *trying* moments for caregivers. They are worrisome because they are *difficult* moments; they are *frustrating*, as well as *demanding*. The sentiments of the majority of participants in the study were more appositely put across by an urban female participant that said, "...cooking is a taxing job. You run around a lot, and that is where most of the work is," (p. # 5-6). Even though bathing the patient is done more than once per day by others; and washing clothes and linen for bedridden patients or those with diarrhoea is also done daily or twice a day by others, cooking proved to be more problematic. Apart from being '*taxing*', it takes up a lot of time too. For example, one urban female participant answered the question on the caregiving task that takes up most of her time by saying, "What takes most time is cooking, because you take time touching this, touching that, and that. By the time you finish doing this and go out to do other work, you would have used up a lot of time," (p. # 4-1).

The major reason why cooking is a *taxing* task for caregivers is partly because patients change food preferences and lose their appetites frequently. This, in turn, also



affects the process of feeding. A rural female participant that indicated that feeding her mother was the task that took up most of her caregiving time said, "Giving her food takes more time, because sometimes she will be refusing [to eat], and we have to force her to eat. And sometimes she gets angry....she feels as if we are bothering her....but we have to make her eat something at least," (p. # 5-1). Therefore, apart from risking censure, the tasks of cooking and feeding require *perseverance* as well.

One urban participant said this about *perseverance*: "You cook something, and if it doesn't work you put it aside, ask what he wants and then cook something else, up until he eats something that stays in his stomach," (p. # 13-3). Another participant said, "Sometimes he says he wants something, and after you have cooked it he says he doesn't want it anymore, that is my problem," (Rural p. # 2-1F1). The participant's sister echoed these words during my next visit. She said:

*You might spend one hour preparing the food he wants. You finish and give it to him, and sometimes he doesn't eat it. He says he doesn't want it anymore, and you will have to start preparing something else that he says he feels like eating, (Rural p. # 2-1F2).*

Another rural female participant also had a similarly representative story about her son:

*The bad thing is that he doesn't eat something for two days. Once he eats something today, tomorrow he doesn't want it anymore....[For example] when it comes to porridge cooked in peanut butter, sometimes he says, "Yes cook it, I want it." And he only eats that for one day. The following day he doesn't want it anymore; he wants margarine in his porridge. Then you use the little margarine you have left, and the following day he goes, "I don't like it anymore," (p. # 4-1).*

All participants were asked if they prepared the patient('s) food separately from theirs. By asking this question I wanted to find out if caregivers were cooking food separately because of fear of contracting AIDS. But what emerged was that most caregivers prepared their patient('s) food separately only because they would have expressed a different choice of food from what the rest of the family was eating, or they had refused what was prepared for the whole family; something they had originally expressed a wish for. For example, a rural female participant said the following about her son: "We cook things at once for everyone, then give him his share. But most times he says in the end, 'I don't want, it is not tasting good for me'," (p. # 4-1). This was a scenario painted by most caregivers in the study.



Apart from coping with the task of cooking many times because the patient has refused eating prepared food, the issue becomes even more complex because patients want to eat more frequently. One female participant said of her father, "...he gets hungry more often, that is why we cook many times...Even when visitors come he says he is hungry, and we have to give him food also, because he is used to eating all the time," (Rural p. # 2-1).<sup>6</sup> Cooking more often makes caregiving even more *demanding*. One urban grandmother said that after her grandson has eaten 'sadza' (staple food) with okra soup, "...he asks for tea soon after," (p. # 4-5). Another one said, "In the evening I cook 'sadza', we eat and go to sleep; but he keeps saying that he is hungry," (Urban p. # 13-3). Another urban female participant also said of her sister:

*...[Y]ou hear her say, 'The way I love to eat these days!' ('Ende kuzoda kudya kwandirikuita'). [Laughs] And I ask her, 'What has happened sister?' and she goes, 'The food I am having is not even enough, I have a big appetite.' I don't know what the tablets do to them, (p. # 14-4).*

The issue of tablets came up in the majority of interviews with caregivers of PWHA. Most of these participants' patients had tuberculosis (TB), an opportunistic disease that has a strong affinity to AIDS, and a few had just gone through their cycle of treatments. Although this participant seemed not to know, many participants in the study had been educated by either health personnel in health facilities, or outreach workers and HBCW about the fact that TB medication increases appetite. Therefore one female participant said:

*Yes, they [hospital personnel] explained that we should give him food before he takes the tablets. And they also said that whatever he eats, it has to be something solid, so that he does not have problems throwing up after taking the tablets... [So] when there is no food to give him, the tablets start reacting in his stomach, (Urban p. # 13-3).*

This is a matter that was substantiated by a Registered nurse that acted as my guide into the first leg of my urban interviews, as well as by most HBCW. For example, one urban HBCW said that when they visit patients in their homes, they are often asked, "Okay 'grandmothers'...what have you brought me that I can eat? I am dying of hunger, and I have defaulted on taking my TB tablets because I have no food." She went on to say that, "...those with TB fail to take their tablets because the tablets need to be taken with food, which they don't have," (p. # HBCW3).



One other urban participant that was looking after a brother and a husband said of her husband: "...the tablets that he takes require him to eat...before taking them. So if there is no food he doesn't take them," (p. # 3-4). She went on to explain how the husband had defaulted on his medication the previous day when he went to the Infectious Diseases Hospital for a review, but didn't have money to buy any food to eat. One participant's wish, which was actually a mirror image of all caregivers' wishes, was "...[to be able] to wake up and prepare some potatoes for him, so that by the time he takes his tablets there is some food in his stomach," (Urban p. # 13-3). Therefore, "[w]hen you are looking after a patient you need money...it requires food that you can cook for him," (Rural p. # 4-1). This demand for food amid deprivation and food scarcity in the family results in *exasperation* and *helplessness* among caregivers.

*Food Demand Vs. Deprivation: A Caregiver's Impasse:* - Caregivers of PWHA are therefore, faced with patients that need adequate food for the tolerance of the TB medication. However, circumstances do not allow caregivers to make this possible, and this makes them feel *powerless* and *helpless*. In a general sense, the following urban participant gives us a picture of the demand and supply of food:

*It is recommended that she does not spend a long time without taking food, because the tablets will start to react negatively inside. It is painful, so she has to have food. Yes. But sometimes I am unable to provide the food, due to lack of money, because my husband is unemployed, (p. # 5-6).*

But this one paints an even more desperate situation, spanning a full day, whereby she has to go out and make money to buy food for immediate consumption:

*In the morning when he wakes up I prepare porridge and he takes his tablets thereafter. After some time, around 9:00am, he wants to eat again, but most times there is no food, so he will eat around 11:00am after I come back from selling at the market. Around 2:00pm he wants to eat again, but still, you find that the food is not enough during the times that he has to eat. And, the TB tablets he is taking make him hungry too. So, it is a very difficult situation indeed, and we have to force things all the time ('Saka zvinenge zvichitooma stereki, ndezvekutongomanikidzira'), (Urban p. # 6-12).*

Apart from the demand for food induced or demanded by the intake of TB medications, most caregivers were also faced with a situation whereby their patients hankered for and demanded food that they could not afford. The effect, however, is the



same, because this also puts caregivers into a difficult *predicament*. And, because they have no way out then, and in the near future, it makes them feel *helpless* and *powerless* to make a positive contribution towards the recuperation and wellness of their patients.

Here are some of the exemplary quotations that can help to put this situation into perspective:

*This one [sister] wants sweet things ('anoda tunonaka')...and no longer accepts porridge. She says she wants potatoes, or beans, and there is nowhere I can get them, (Rural female p. # 1-1).*

*As a patient she needs...many different things. Right now she might cry for...[incomplete sentence]. There are times she used to ask for something, and sometimes I wouldn't know where to start, and I wouldn't be able to give it to her...because I would be having absolutely nothing, (Urban p. # 11-1).*

*He [father] usually prefers 'sadza' with dried Kapenta fish ('Matemba'), potatoes, okra soup, and fish....We can easily get okra, but we cannot afford to get potatoes and fish regularly. And we can only get Mazowe Orange Crush and other drinks when visitors bring some for him, (Rural female p. # 2-1F1)*

*I don't want to lie to you, most of the time we cannot afford to buy her favourite foods, such as potatoes, eggs and 'Matemba' as soon as they are finished. With this type of money that we have to look for, it is a big problem.... In fact, I should say all things that are purchased, we can only buy after a long time, (Rural female p. # 3-1).*

*You know, people sick with this disease [AIDS] sometimes want juicy drinks, fruits, etcetera. So she sometimes asks me for these, and then I don't have even a cent in my pocket. That is very difficult for me, (Urban male p. # 1-7).*

This sense of *helplessness/powerlessness*, coupled with *desperation* is more poignantly portrayed in the following discourse:

*These days he asks for things that I don't have, and there won't be any money to buy them with.... I get stressed up. What worries me is the fact that some days I won't be having anything to give him [brother, who was sicker than the husband] to eat....You try to ask from next-door neighbours... 'Please, isn't there anybody with...', maybe I don't have even corn meal then, relish or sugar. And sometimes he can shout at me to, 'Prepare porridge for me!', and I don't have the sugar or even the corn meal. That worries me a lot; because you ask other people and they tell you they do not have. I go back and tell him, 'I have failed to find*



*any,' and he goes, 'Ah! But my stomach is hot with hunger, it's hot sister, why don't you go try to ask around some more, my stomach is hot... (Urban p. # 3-4).*

Such persistent demands from a grandson led one caregiver to say, "...That's when I give up," and it leads her to also ask herself these rhetorical questions, "...What else can I do? ...Should I kill myself in order to get food? Should I go and steal? Where do I get it?"(p. # 4-5). She also went on to say that she "...find[s her] head spinning because [she] doesn't have those things," that her grandson and daughter patients ask for. In the end, the *helplessness* that most caregivers find themselves in, forces them to wait for any visitors that might bring some change or foodstuffs for the patient, as participant 2-1F said above. This is the way most caregivers could cope with deprivation of this magnitude. For example, one female participant said, "If I happen to have received some money from a well-wisher I buy bananas or a soft drink for him," (Urban p. # 13-3). And another rural female participant said that her son immediately asks her to buy some bread any time "...there happens to be any money left by anyone that comes to see him..."(p. # 4-1).

Under normal circumstances, because of deprivation, most poor families do with fewer meals per day. Therefore, when they make an effort to find food to prepare for a patient, it is an extreme case of *sacrificing* the few available resources. For instance, this rural female participant said:

*The problem is that food is hard to come by....In the morning we might cook porridge or 'sadza' with vegetables...In the afternoon we might go through the day on an empty stomach because we won't be having anything to cook for her. Then we eat in the evening when we get the relish, (p. # 5-1).*

And another one said, "...if it's just us, we have tea in the morning, spend the whole day [without eating anything else], and then have 'sadza' in the evening. But with a patient, we cannot have only tea, or cook once for him...he gets hungry more often [and] that is why we cook many times, (Rural p. # 2-1F).

Apart from pressure coming from patients that demand food more frequently, as well as food out of reach of the low-income caregivers, there is also considerable pressure that caregivers exert upon themselves. Most caregivers did realise that patients need to be fed nutritious foods in order to move to recovery faster. But "...such foods



cannot always be available," (Urban p. # 12-2). The fact that caregivers have this knowledge, their inability to provide this 'good food' puts them into the same *impasse* that I described above. This state of affairs was more aptly described by an urban male participant who said:

*The only thing that bothers me the most is that there are things we cannot provide her; things that people like this [i.e., that are HIV+] are recommended to take, such as fruits, and [other] nutritious foods," (p. # 1-7).*

While other households face a chronic shortage of food and money, for those that had a relatively 'better income', by "...the middle of the month there is usually nothing [i.e. good food] around..." (Urban female p. # 12-2) for the family to go on.

*Seeking Medical Help*:- Seeking medical help at the local health centre or hospital is also part of looking after a patient. For PWHA, the need for more frequent trips is necessitated by the recurrence of opportunistic illnesses, while at the same time curtailed by the unavailability of hospital or consultation fees, and geographical inaccessibility of health facilities. However, it is the 'going', or the journey to and from the hospital that concerns us here. It is the tribulations associated with the efforts put into going to seek medical help that are pertinent to the analysis of experiences of caregiving. With regard to the repeated visits, one rural participant said: Tribulations

*We went for the first time and he got admitted for three days and got discharged. He came home and stayed for a little while and the illness started again after the tablets got finished, and they said he must come back. Then I took him back, got some tablets and came back home. Then we went again...This third time is when I told the doctors I couldn't move around with the patient, and asked if I could come and pick the medication myself," (Rural p. # 4-1).*

Owing to lack of money for transportation, and lack of proper roads, the most common means of taking the patient to a health facility for rural participants were: walking on foot, by wheelbarrows, in ox-drawn scotch carts. The less common means in the rural areas were hitchhiking and taking buses, for those living close to a the highway. Most urban participants took their patients to hospital by public transport, and transport costs were the greatest barrier. Some who could not afford transport costs had to walk, such as this participant who said, "When the illness started it would take us two hours" just to go



to the hospital, "because walking was a problem for him," (p. # 13-3). However, because of the sheer enormity of the burden of taking a patient to a health facility in the rural areas, I shall only concentrate on the experiences of rural participants.

Distance permitting, mobile patients are easier to take to hospital, because walking is an option. As the patient's condition worsens, other modes of transportation would have to be sought. Some participants indicated that some bus operators refused to accept very sick patients onto their buses, so they "...have to wait for 'lifts'" [i.e. hitch hiking]. For some participants, taking a 'lift' or a bus does not make much difference because there is still that distance from the bus stop to their home, or bus stop to hospital. For example, one young female participant said, "When we get to the drop off point we have to carry her [mother] on the back because we won't be having money [to hire a car]" (p. # 5-1). This family had no option of using an ox-drawn cart, because they had neither cattle nor cart.

However, for a family with a wheelbarrow, the *burden* is somewhat lessened, but not eliminated. I say this because one of the participants that lived about one kilometre from the bus route said she had to wake up at six to push her husband in a wheelbarrow to the bus stop. She went on to say that they have to make several stops on the way, hence "...it takes one to one and a half hours to get to the bus stop," (p. # 6-1). Time taken pushing a wheelbarrow is even longer for those living further away from the bus route. For example, a participant that lived about 6 kilometres from the hospital, where there was no option of taking a bus or 'lift', said that it takes them "...about three hours" (p. # 8-1) to push her mother to the hospital in a wheelbarrow.

The task of taking a patient to hospital is even more daunting for those that have to walk to the hospital. Some of the rural patients had to walk distances of up to 11 kilometres (one way) to the hospital. Citing the reason for not taking the bus or 'lifts' for such a distance as lack of money, one participant said that they "...leave this place [i.e. their home] around 7:00am...[and] get there [hospital] around 11:00am," (p. # 7-1). Another participant that lived a couple of metres away from the bus route, requested the hospital to allow her to regularly come and collect her son's medication owing to the fact that she "...[could] not carry him around" since he was "bigger than [her]" (p. # 4-1). However, this did not lessen her *burden*, as can be gleaned from the following dialogue:



**I:** So you go back whenever the tablets are about to get finished?

**P:** Yes, I go when they are about to get finished.

**I:** The first three times you went, did you go by bus?

**P:** We hitchhiked ('taikwira malift'). They were refusing him onto the buses...

**I:** And you could easily get the money to pay for the trip from here to the hospital?

**P:** I used to get it. I would keep some, from the monies left behind by those that came to see him. But since I am going alone now, I go on foot....I go and come back on foot.

**I:** You go to the hospital on foot? [distance = 10 km]

**P:** I go and come back on foot because I can no longer get the money [for transport].

**I:** How long does it take you to go and come back?

**P:** I walk, sometimes I get back here late, but I would have asked someone to do the cooking for me. Because I would not be having the money for the outward and return journeys....People take buses, but if you don't have money you go on foot.

**I:** How much time does it take you to go to the hospital?

**P:** It's quite some distance, to walk from here to Mutoko Hospital.

For this sixty-one year old participant that had a grade two education, how long it takes for her to walk to the hospital might be something unfathomable, but it sure takes up her whole day, such that she gets back home 'late'. The same question was repeated in a different manner during the next interview, and she answered that it was "...quite some distance..." Regardless of the fact that I did not get from her how long it takes her to walk, I got the impression of a *painful* journey from her words, "It's quite some distance..." The journey must have been painful not only in the *physical* sense, but also *emotionally*, because she wasn't able to get home in time to cook for the patient and her grandchildren. Also, having to ask someone to cook for her all the time must have been a humbling experience as well.

While this participant's pain transformed from that of having to take her adult son to hospital by 'lifts', whereby she sometimes had to carry him between the bus and home or hospital, or from ward to ward, to that of having to walk to the hospital, some had to endure the walk from home to hospital with an ailing patient. One such participant had to



walk a distance of about six kilometres to the hospital. Even if there were a bus route, she would not have afforded the transport expenses. This dialogue with her portrays a sense of physical *pain* from walking the long distance, carrying two babies, and supporting the patient with her arm.

**P:** ...*transport here is a problem. Even when we go to the hospital, we go on foot; slowly, with this child [her older child] walking in front, and this one [her baby] on my back.*

**I:** You carry these two?

**P:** *Yes, I carry one [her baby] on this side, and one [patient's baby] on the other side, and the bag with nappies on one side, then I hook her hand [patient's] into mine like this [gestures]....*

**I:** Apart from being told to come on a certain day, aren't there times when she gets so sick you wish if it wasn't too far you would have taken her to the hospital anyway?

**P:** *It happens, but there is nothing I can do, because my shoulders get sore from the pressure exerted by the baby back carrier ('mberekō'), so walking becomes a problem* (p. # 1-1).

Therefore, caregivers endure physical pain when faced with the daunting task of taking patients to the hospital, more so when they have to walk with painful slowness as indicated by this participant. There is undoubtedly '*emotional pain*' as well, when one cannot afford to take a patient to the hospital because of transport costs, or the inability to take the pain, as stated by the above participant. '[T]here is nothing I can do' also connotes a sense of *powerlessness*, on the part of participant 1-1. Similarly, the inability to garner resources, such as other modes of transportation (e.g. ox-drawn cart) or money for transport, in order to make the hospital trips more tolerable, make caregivers feel *helpless* regardless of their desire to help their relatives.

#### Caregiving versus Household Tasks: The Juggling Game

As I have already shown above, caregiving tasks are numerous, and time-consuming. When household chores and other income generating activities fall onto the shoulder of one person, the caregiver, one has to learn to juggle all those tasks well, in order to maintain some semblance of normality in the household. All participants, except for one rural and two urban male caregivers, were up to their elbows with both caregiving tasks and household chores. All participants, except one rural adolescent caregiver, were



also strongly involved in activities that generated either cash or food (i.e. agricultural activities) for household consumption.

One urban female participant that lived with her husband, but made daily visits to look after her sister (and a mother with a stroke) in the same suburb, revealed her personal experience of juggling activities in her house, and in the patients' house:

*When the situation is bad ('Pazvinenge zvakapressa...'), I can wake up around 4:00am, wash my clothes and clean the house, and see to it that I finish all those chores [at my house]....[When] I am done...about 6:00 or 7:00am I am here. ...I usually see to it that around 7:00, 8:00 or 9:00am I am done with all household chores here, and I start giving them food, both her [sister] and mother, as well as ensuring that they have bathed (p. # 14-4).*

Another participant that was looking after a son, and living with grandchildren, also told how she managed to accomplish these tasks, as well as agricultural activities:

*...I have school children [i.e. grandchildren], so I wake up and cook for them...After they have finished eating I...take my dish and run to do the washing. Then I come back and go into the fields, (Rural p. # 4-1).*

Apart from dealing with many tasks in limited time, there was also gleaned a sense of dissatisfaction with the quality of work performed, as aptly put across by this participant:

*[W]hatever I do, I do hurriedly, because I will be trying to push things so that I can accomplish things on the other side [i.e. in fields and garden], so that the children can have food, while at the same time trying to see to it that my patient gets well, (Rural p. # 1-1).*

Role Conflict:<sup>7</sup> For many participants, 'juggling' led to role conflict, which was very real and very problematic for them. For example, the rural patient quoted above said:

*What I do when I get up is, I cook porridge for the patient first, she takes her tablets, and then I go out. Around 10:00am I come back, as I have just done, then I prepare what she wants to eat before I go back to the fields again. But it's a problem ('asi idambudziko'), because right now I haven't even planted my groundnuts. I also have a portion to plant rice, but I have not yet planted anything. So it's a real problem, (p. # 1-1)*

An urban participant that I asked if there were any things that she was failing to do because she no longer had the time, or had too much work, replied:

*I can't do all I want to do, and all he wants done. And the patient thinks you do not care about him, or that you are just spending the whole day at the market [for nothing]. It is a real problem (p. # 6-12).*



In this case, both wife's (caregiver) and husband's (patient) expectations were perceived to be unmet. Another rural participant also showed great concern for the deluge of responsibilities that had piled up on her. When I asked her if the way she was doing her agricultural activities was still the same as before her son was brought from Harare, sick, she said:

*It is not the same, because right now I work in the fields for a while and start thinking that the patient has to eat now. As soon as I get into the field, I also start thinking that the school children are about to come back [and also need food] ...[As a result] my work lags behind, because of the patient and the family. The way I used to handle my work is no longer the same, because I am now constrained by the presence of the patient. Moreover, I have to delay getting into the fields because I have to do his washing first... Sometimes I get into the field in the afternoon, after finishing everything, from washing, hanging the clothes to dry, and then cooking...It hurts (p. # 4-1).*

It is evident here that the caregiving role is in *conflict* with the family provider role. There is also a hint or *role distancing* (i.e. subjective detachment from the caregiving role), and a sense of lack of *accomplishment*. The following urban participant, who felt perturbed by the fact that she could not be with her sister around the clock when it looked like she was losing her mental faculties, poignantly expressed the same feeling of lack of *accomplishment*, or inability to fulfil one's roles:

*This is something that was of great concern to me, because at home my husband needs my support, and here they [i.e. patients – sister and mother] also need my support. And with all these things on my plate I have to play a balancing act, seeing to it that I don't abandon my marriage, as well as my relatives. It's impossible, yes, ... (Urban p. # 14-4). [My emphasis]*

**Role Overload**:- I have already established above that the seriousness of the illness determines the nature of the caregiving tasks. Most of the patients that the participants in this study were looking after were on the serious side of the serious-not serious continuum. The caregiving tasks for most participants were therefore, quite intense. The more intense the caregiving responsibilities were, the heavier was the workload for caregivers. Combined with household chores and other activities, such as generating income, the enormity of the workload was immeasurable. When workload



becomes unbearable, such that one barely copes, it translates into *role overload*; one becomes *overwhelmed*.

Considering caregiving duties alone, there were, for example, some participants that needed to change their patient "...about eight times...[a]ll during [one] night..." because of diarrhoea (Urban p. # 11-1). Some would "[s]ometimes sleep only two hours the whole night," (Rural p. # 6-1), because they would be tending their husband's aching legs. And, besides cooking and tending the patient, some of the rural participants needed to walk distances of up to a kilometre to go "...to the river to wash..." (p. # 4-1) the patient's clothes. Lifting bedridden patients also came across as one of the most arduous tasks. One rural young male participant, for example, had the responsibility of lifting his father to put him into different sitting positions, taking him to sit/lie outside, bathing him, and helping him with toileting. On my first visit, I discovered that the father had not been bathed for over a week, because there was no one to help him lift his father. Since he was bedridden, with bedsores, my chief informant and I decided to help change the bed linen, his wet trousers, as well as put the patient in a different lying position. This was no fun. It was a task that took us about fifteen minutes, but it was an invaluable insightful experience for me in particular.

Coupled with other household responsibilities, therefore, the tasks inevitably take a toll on someone. For example, one urban caregiver said, after a hard day's work, "[a]t times I feel so tired that my body just refuses to get up [in the morning]," (p. # 14-1). This participant looked after a sick sister and mother, on top of being a housewife at her own home. Hence she said to me, "I have two jobs...[and] there comes a point when it becomes hard to cope", such that on days when her sister was strong enough to help with the dishes, she felt glad because "...the workload would have been reduced..." for her.

The following two excerpts from an urban and a rural participant articulated the issues of *role overload* and *role conflict* as pertinently as to sum up the views of most participants:

*[T]here is too much work for me. I have to go and order the goods to sell [very early in the morning], come back to cook breakfast, then go back to arrange my tomatoes at the market stall. After selling [i.e. day's work], I have to come back home and cook supper. Therefore, I have serious time constraints....And I do not have adequate time for the things*



*I must do.... People say whatever they say, but they do not realise how troubled I am. If I stop selling, I know he will die of hunger (p. # 6-12).*

*There are two patients here, the mother [i.e. her sister] and her baby. I have my own child. So what I do is attend to this one, then attend to the other one, and then the other, and that takes a lot of time....[On another day] By the end of the day I find that my body is exhausted. That is why I said I feel back pains, because its work throughout, and there is nothing easier. The patient wants things done for her, and the fields need to be attended to. There are three jobs, in actual fact: I am doing work in the garden...[and] ... in the fields, I am caregiving, and the whole family needs my attention. It is a real problem...[A]ll those things have to be done by me; and that calls for a lot of tolerance ('moyo muchena'),* (Rural p. # 1-1).

According to this participant, her plight drew sympathy from her husband, who had *appraised* and *validated* her situation the previous day by saying, according to the participant, "It would be better for me to quit my job [at the local grinding mill], because I can see that you can't manage the work around here. You can't do anything more," p. # 1-1).

In another case, such unsolicited *appraisal* and *validation* acted as an inspiration to a caregiver. This sixty-one year old caregiver said she had a real "...burden, because it is not easy to have a patient...go into the field, and cook for school children," (Rural p. # 4-1). According to this participant, because of this feat, her sisters-in-law ('anatete')<sup>8</sup> would say to her:

*Ugghh, you are actually putting us to shame by the amount of work you do here. How are you managing? You have children that go to school, and they need clothes washed for them. The patient needs clothes and blankets washed for him, and he also needs to eat. And you also cook for yourself and the other children that don't go to school (p. # 4-1).*

And her modest reply to them was always, "There is no alternative. God is the one that makes me manage. If God is on your side and you are healthy, you can achieve whatever you want to achieve," (p. # 4-1). She also went on to say:

*What I can only ask God is to make me strong so that I can conquer the odds, because there is no one else that can help me with work like this...Yes....it's a burden to me, yet there is nothing I can do about it.*

*Workload and Social Isolation*:- All participants in the study lamented the loss of time to partake in socio-cultural activities that were originally part of their daily lives, before their patient(s) became ill. The inability to participate in these activities, or to visit



relatives, which is a vital component of reciprocal interactions between kin, is caused by either too much work without respite, and/or not having someone to step in and look after the patient in the caregivers' absence. On the other hand, the inability to visit relatives is also caused by lack of money for transportation, assuming they do have some time to spare. Whichever way it comes, this inability to interact with friends and kin leads to *social withdrawal and social isolation*.

A good example of activities that are forgone came out from the words of this rural participant: "...Even *travelling* I no longer do. Even *funerals* I no longer attend, because there is no one here that I can leave behind to do hard work like this, there is none...but it is a real burden on me, yet there is nothing I can do about it," (p. # 4-1). Another example is that of an urban participant that was looking after a husband and a brother, with one-year old twins in tow. She had absolutely no one else to send to do even the smallest of errands or household chores. She said to me:

*Even right now I can't even think of going anywhere, such as to relatives to tell them, "Please I don't have even a cent on me," I have no chance to do that. The only time I can afford to go away is when I go looking for firewood to cook with. I cannot go anywhere away from this home, never. It's impossible. ('Kuti ndibve panoapa hazvitomboita, hazvitombokwana kana. Hazvitomboita'), (p. # 3-4).*

The socio-cultural activity mentioned by most participants as being out of their purview, however, was going to church. When I asked one participant if she was able to go to church, given her caregiving responsibilities, she said, " I can't even go...When things have a grip on me like that, three months can go by before I go to church (p. # 7-1). A number of participants indicated that their continuous conspicuous absence from church services often acted as a distress signal to the congregation. Hence such comments were made: "...It is my friends now who will begin to suspect I am not coming to church because I might be sick" (Rural p. # 7-1); "...And they also notice my absence from church, and they know that I have encountered problems and they send people to check on me..." (Rural p. # 3-1). Even though church representatives were often sent to check on non-attendees, and pray with them in their homes, the frequency might not have been enough to offset the effects of the *social isolation*. For example, one rural participant that belonged to the Methodist Church said:



*[T]hey come say once in two months, on a Wednesday. When they know that at a particular home there is a problem; that is, if they do not see me at church for a good number of days, they come and hold their Wednesday congregation here; sometimes on Fridays instead, (Rural p. # 7-1).*

The following dialogue with an urban member of the Salvation Army better puts this experience of *isolation* into perspective:

**I:** During these times when you have been looking after your children, have you been able to go to church?

**P:** *No, I have not had the chance, because there was no one to leave behind to look after the patients.*

**I:** But it would be your wish to regularly go to church?

**P:** *It would be my wish to go to church, but because of illness in the family you lose all that interest.*

**I:** If you could get someone to leave behind, would you go to church?

**P:** *I wouldn't go, I don't want to lie to you; I wouldn't go. Where would my heart be? You can't pray, you will end up praying what is at home because that is all you have on your mind, the health status of your children back home. ('Handaimboenda, handidi kureva nhema, handaimboenda. Mwoyo wacho ndinenge ndakauisa kupi. Haunamateka, unenge waakutonamata zvirikumba kwako chete ndoozvaunongoona. Magariro akaita vana vako kumba ikoko,')* (Urban p. # 5-6).

The devotion to kin, in this case, leaves the caregiver torn between spiritual gratification and seeing to the welfare of her two sick children. The latter takes precedence, plunging the caregiver into further *self-marginalization/isolation*. Finding a substitute caregiver, therefore, does not mean peace of mind and a return to normal participation in socio-cultural activities for a devoted caregiver. The same perception came into focus in my interview with another participant who said, "...there is no one else that can help me with...hard...work like this....[B]ut it's not proper to leave a patient like this in the hands of someone," Rural p. # 4-1).

### Caregiving and Caregiver Health

Most of the participants indicated that they had never been to a hospital or clinic to present with any health problem of their own in the past six months. This is understandable, considering the low-income status of participants in the study, and the expenses that would be needed for both user fees and buying prescriptions. Another



question that was dropped early in the study because it did not elicit much useful information asked participants to give a subjective appraisal of their health status. Most of the initial participants misconstrued its essence, and it came across to them as a question saying, 'Now that you have your...that has AIDS, so what is your health status yourself, or where do you see yourself?' A more fruitful question, however, asked (towards the end) for participants' experiences of ill health, in its broadest sense, in the face of the daunting task of caregiving. Another fruitful question asked participants if anything had happened in their life during the past month to cause them great stress. Other indications of ill health were gleaned from tangential references during interviews. Participants expressed varied experiences with mental and physical health. Most of the participants made reference to mental health than to physical health.

*Caregiving and Mental Health*:- Many participants perceived a link between caregiving and mental health, as succinctly put across by a participant who said that the problem she had with work pressure was "...that of mental stress..." (Urban p. # 12-2). The most common stressors or sources of worry mentioned by participants were: inability to cope with role demands (role overload); the illness as a whole; particular illness episodes; the general state of deprivation, and inability to satisfy the patient's basic needs. With regard to the illness in general, here is what participants would say:

*I don't sleep, I don't sleep, it just keeps worrying me....There are times when I cannot eat, thinking, "Now, as things are, what are we going to do?' Because...I am not working, and she might just die in that house while I do not have even a cent....There are times when I end up talking to myself. I will be thinking of our deceased parents. Because my father was a manager in a [municipal] bar, and I suspect it was this virus [HIV] which killed both my father and mother....If I was working I might end up screwing up things, because my mind will not be on what I am doing, but thinking about the illness in the home....[Another day] ...With me, I end up forcing myself to drink beer...It is alcohol that helps me[when I am stressed out] ... (p. # 1-7).*

*Recently I noticed that while I was looking after patients [three], I was actually worse off than them. I had less weight than the patients I was looking after. [Why?] I think that was being caused by mental stress ('Ndofunga dzanga dziri pfungwa')...(Urban p. # 10-1).*

With regard to illness episodes, participants would say:



*In fact, I have two patients, and...sometimes one of them gets seriously sick...and I lose all hope. It gets to a point where I get deeply disturbed by it (Urban p. # 14-4).*

*This girl's illness was troubling my mind.... She was in too much pain....[And when my son got seriously sick recently] I was deeply troubled. My heart was 'thinking', "He didn't die from TB last time, now this one [herpes] is going to kill him. I agonized over this very much; it hurt (Urban p. # 5-6).*

This worry about patients' illness or illness episodes always made caregivers to be unwilling to leave their patients behind, because:

*...you can't get that out of your mind. It is always there in your mind. The problem is, when you have gone somewhere, such as the days when we are asked to come to Mother of Peace. When you go...it's hard to sit down comfortably with others. I will be thinking how he is doing back home, without anybody to help him, asking myself what he has eaten. You can never get that off your mind... (Rural p. # 6-1).*

According to another caregiver that indicated she had lost weight above:

*When you have caregiving duties, sometimes even going away to town can cause you a lot of stress, because you will be imagining what is happening here [i.e. at home] ....[And] there are times when a patient gets seriously ill that you can't sleep at night... You can go the whole day without eating. You will be forcing them [i.e. three patients] to eat but it becomes impossible for you to eat, because such things weigh heavy on the mind. You start thinking a lot, (Urban p. # 10-1).*

Sometimes even what the patients themselves do can exacerbate the caregiver's anxiety and stress. For example, one rural participant said of her mother: "When she is seriously ill, she might say things like, 'Phone my son [in Harare] to come, [because] I want to say good bye to him.' That gets me worried a lot," (Rural p. # 5-1). Another rural participant also reported a similar concern regarding her daughter:

*At times she comes to me and goes, "I am dying mother. What should I do mother?" And she has her hands all over me...So we become two patients.... Yes, sometimes I get stressed out from thinking too much, you see. It is possible that one can become sick because of thinking too much, (Rural p. # 7-1).*

In these two cases, the thought of their patients dying, though inevitable in the case of AIDS, became an unfathomable, stress-generating concern.

Most participants also indicated that the constant worry about their general state of deprivation was also a source of mental ill health. For example, one participant said



that she “...get[s] stressed up...[because] on some days [she] won’t be having anything to give [her] patients to eat,” (Urban p. # 3-4). Another participant, whose wife had died a few months before said that his mind “...gets all mixed up...” (‘ndovhiringika pfungwa zviya izvi’) because “...sometimes [he] ha[s] no food for the children,” (Urban p. # 9-8). His most stressful experience during the month prior to our conversation was when the child’s illness got worse, as well as his “...inability to get money for transport to go and visit him at the hospital [once he was admitted], and [his] own ill health...” When I asked him if he thought his caregiving responsibilities affected his health he said:

*To tell the truth, ...it affects my health, because...if you consider our living conditions, and the way they [i.e. children] cry like that, I find that depressing when I think about it. When I ask myself, “Okay, now what can I do about it?” I just run out of ideas, and don’t know what else to do. It troubles me quite a lot, you see. It gets my brain all mixed up. And since I have always been a sick person [epilepsy], my mind easily gets mixed up.... So, yes, I know that this is not healthy for me ('hazvinautano hwakanyatsondinakira chaizvo chaizvo').... These problems can all happen at the same time, and my mind can get mixed up just like that (ndoviringika pungwa zviye izvi')...(Urban p. # 9-8)*

The importance of the general state of deprivation for this participant’s mental health is underscored by the fact that he linked the two on two separate occasions, answering the different questions.

Another urban participant looking after a daughter and a grandson said that the demands from her patients for things that she could not afford to procure for them made her “...head spin...,” a condition she said could actually make one “...[to] go mad...” (p. # 4-5). Speaking about such situations, she said, “You just find your tears streaming down like this, and you say to yourself, ‘God, please take me for I am tired of this.’” While the following participant who suspected she was also HIV+ worried about her daughter’s illness, what stressed her out most was the fact that she could not foresee anyone looking after them in the event that her own health continued to deteriorate as well:

*[My] patient is sick, ...and I think my body is also not healthy. So who will manage to look after both of us, in the event that I eventually break down, like is happening now? Who will manage to look after us? That is what occupies my mind the most (Rural p. # 7-1).*



Being a widow, unemployed, without any social security to fall back on, and with children (including a patient) to look after, such mental anguish is understandable. Apart from these experiences, feelings of *powerlessness*, *despair* and *isolation* are also evoked by the lack of someone to give you their ear. This comes out eloquently in the discourse of this widow:

*Yes, I have 'any thoughts'; that is unavoidable. There is only one of you [i.e. herself], and there is no one to tell [what's going on]. How can worries not haunt you? ... The situation needs someone that can say to you today, "...Things will go this way, and that way." But when you are the only one, the situation you saw yesterday, you will see again today. You are the only person [in charge]. So it is inevitable that it would make your mind spin ('Zvino saka hazvirege hazvo kudii? Kukutenderedza musoro'). But you just put the matter in God's hands,* (Rural p. # 4-1).

Caregiving and Physical Health:- Caregiving duties, particularly where the workload (i.e. *role overload*) was considerable, which was the case with many participants, were also perceived to impact on physical health. The health problems identified by most participants include: back pain, headaches, general pain in the body, and fatigue/physical exhaustion. For example, one participant said that by the end of a day's work, she felt "...pain in [her] back...", and also experienced general body exhaustion (Rural p. # 1-1).

For a participant with a bedridden husband, he had to be lifted a number of times per day, including taking him out into the sun, taking him back into the house, lifting him into a chair, bathing him, and putting him into bed. According to this participant, there are "...times when you feel pain in some parts of the body..." (Rural p. # 6-1). She went on to explain: "He is a bigger person than me, so when I go to sleep my back aches a lot. That bothers me a lot..."

Another participant told how, in the face of work overload, she persevered in order to make the patient presentable to visitors:

*Sometimes it is when I sit down like this that I really feel that I am tired. Yah, I feel that. When I am up and about I do not feel it. But God gives me the courage and strength, because sometimes I think that I would not be able to do anything when I wake up the following day. But I wake up strong, because you don't want visitors to come and find the patient in a repulsive state, because you have not bathed her or something. That's*



*what gives me strength ('Ndizvo zvinongondishingisa'), (Urban p. # 11-1).*

This perseverance however, results in fatigue, which is detrimental to her physical well being. Perseverance results in overworking, which, "...during some days [makes] your body just to feel tired..." (Urban p. # 14-4).

*Caregiving and Health: A Holistic Focus:-* Although many participants talked about the effect of caregiving responsibilities on either mental health or physical health, an equally good number had a holistic focus. They had a sound perspective on how their socio-psychological and physical health were impacted by strenuous work schedules, as well as by 'thinking too much'. The same participant that talked about *persevering* in the section above better expressed the connection between mental and physical health. When I asked her if she had experienced any health problems since she began looking after her sister she said:

*Yes...it has got to that extent, and I can't go to the hospital. Looking after a patient is a difficult thing to do. I say so because sometimes you feel pain in your heart, just by looking at her, the way she is suffering. You feel your body, [incomplete thought] or if you happen to have deep thoughts, you can feel as if it's now in you, and you can experience chest pains. There are times when I feel that myself. But then, you get to think, "I am in a better position, so if I sleep, what happens to the patient?" That pushes you to wake up and cook for her, and do whatever else for her. But it is a difficult situation, (Urban p. # 11-1). [My emphasis]*

In this case, just looking at the patient, as well as empathising with the patient, or thinking deeply about the situation (or illness), which is akin to mental stress, transferred into pain in her heart. That is, through transference, she experienced the *anguish* that her sister was suffering. In this experience, there is also a sense of *despair* and *powerlessness* felt by this participant.

A female participant that said that caregiving responsibilities made her mind to "...work overtime..." was another good example of the linkage between mental and physical health. Therefore, "...thinking a lot..." about not being able to pay rent, and running around doing caregiving tasks were perceived to "...affect my brain, even my body," the participant said (Urban p. # 13-3). She went on to say:

*Right now I have lost weight, because of thinking too much, because I am the only one that supports him, and I am always thinking where to get the next meal. Even blankets, if you wash them too often, they won't*



*last, they tear, and you again start thinking where you are going to get new ones. All these are thoughts that continue to 'eat me up'. You [i.e. herself] are always thinking where this illness is going to lead you. And when it comes to the children, the moment they come back from school, they look up to you [for everything]. Their eyes are always on you. And this also adds on to the thoughts I have talked about. In the end you hardly ever have a break.*

When I asked this participant whether 'thinking too much' affected her health, she said, "Your health deteriorates ('hutano hunotodzikira'), because even the food one eats doesn't go down well," (p. # 13-1). Thinking too much about the illness and where to get resources to use in the home was also perceived to cause one participant's blood pressure to go up. And when blood pressure "...goes up, my legs swell, and it bothers me," said this participant (Rural p. # 3-1). 'Thinking too much' was also perceived to cause headaches, "[b]ecause there are times when you think too much and your head ends up feeling hot from thinking," (Rural p. # 8-1). One participant that said she "...keep[s] pushing [her]self..." in order to accomplish all the required caregiving tasks went on to say; "...[but] sometimes I feel tired easily. Plus I easily start to think too much...(Plus pfungwa dzinobva dzakasira kundibata)," (Rural p. # 7-1).

Whether it is through 'working too much' (*job/role overload*) or 'thinking too much', or the combination of the two, there is a clear indication that the caregivers' lifeworld is full of perceived threats to physical and mental health. These threats might or might not be at par with threats faced by caregivers of patients suffering from other terminal illnesses, but the threat of contracting the AIDS virus is an objective reality that looms large and menacing on the horizon of caregivers' *lifeworld*.

### Fear of Catching AIDS

There was a lot of *anxiety* caused by the fear of contracting the AIDS virus, particularly from those participants that knew and acknowledged, or suspected that their patient was HIV+. There was also fear of catching TB. This was not surprising, since many people associate TB with HIV+ status. This is not a baseless assumption, since TB is the most common opportunistic disease to afflict PWHA, and the majority of the participants' patients in the study had TB.

A good number of participants had heard, either through health education



campaigns, outreach health workers, or general word of mouth, of the ways AIDS is transmitted, and were seeking confirmation from me. Others might have just been plain ignorant about it, but sometimes it was difficult to tell who had the knowledge or who didn't. For example, after the interview was over, I asked one participant if she had any questions, or anything she wanted to elaborate on, and she said:

*I wanted to ask this: When one washes the clothes, won't one contract the disease? Or these ones [referring to brothers] that deal with the bedpan, and give him [i.e. father] a bath and other things? ....It might be the case that one has sores on their hands when you do the washing, won't we catch it? (Rural p. # 2-1F)*

In this case, the participant's mention of 'sore', implying that the AIDS virus would get into one's body through a sore was a good indication that she just wanted confirmation from me. The fear of catching AIDS was nonetheless evident in her voice. A good example of a participant that was not sure whether or how she might contract the AIDS virus through contact with any of her two patients (i.e. husband and brother), but unmistakably afraid of contracting AIDS, responded to a question on the day-to-day hurdles she encountered as a caregiver by saying:

*...But what I need to know is, since I handle my brother's bedpan when I go to empty it, wont I catch the disease that he has through that? Because I handle the bedpan with my hands, as well as give him a bath....[later] But with my husband, what worries me is that he suffered from TB before we got married, and he was told it had gone, after undergoing treatments like the one he is going through now. After we got married he told me he once suffered from TB, which had since been cured, but it has come back again. So I am not sure whether it is ordinary TB, or it is TB related to these other things [AIDS]. That is what scares me ('Saka handizive kuti iTB chaiyo here, kana kuti iTB yezvimwe zvinhuwoizvo, ndoozvirikundityisa ipapa apa'), (Urban p. # 3-4). [My emphasis]*

When I suggested to this patient that it would be ideal for her to go for an AIDS test in order to allay her fears, she sounded all for it. She liked the idea, but immediately asked if it required money. Without money for an AIDS test, this participant would remain with her *apprehensiveness* and *despair*, because she had no means of changing her circumstances. This was the same participant discussed above, who would not stay in the brother's room to feed him, but placed food on the husband's lap and left the room. This behaviour, therefore, could have been caused by one of two things, the stench



emanating from the room, or *fear* of contracting AIDS during the process of feeding her brother.

Another participant also seemed unsure of the ways in which the AIDS virus is transmitted when responding to my question on whether she needed to know anything regarding caregiving. She repeated to me the same questions she said she had previously asked the local HBCW: "When we are looking after them [i.e. PWHA] like this, what do we do with their left-over food? Also, when we give them a bath, what do we do?" (Rural p. # 4-1). When I asked her what she had in mind when she asked that question about food, she said, "I was wondering if it was okay for me to give the leftovers to the children." However, whether this participant knew the routes of transmission or not, the reality is that she was afraid, for herself, and for the children.

Most participants, however, were more *apprehensive* about contracting the disease than needing to confirm their suspicions about the routes of transmission. One participant that was looking after three siblings, with the fourth having died three months previously, expressed her wish for getting support directed at "...go[ing] to the hospital often, for...TB...check ups..." (Urban p. # 10-1). She went on to say that "...even the blood needs to get checked up... regularly..." Surrounded with these many patients, this participant might have been worried that she had already contracted the AIDS virus. A similar response to the question on desired support was: "...In fact, I am worried about my health since I am in the middle of all this. So I am thinking how I can get support so that I can tell in good time where I stand. That is something that worries me also," (Urban p. # 14-4). A male participant that seemed unsure but sounded knowledgeable about how AIDS can be transmitted also said:

*I am constantly worried about my own life, because we are dealing with a virus ('hutachiwanaka uhu') here, which spreads. But I don't know whether it spreads through an injury or not, because I might get injured working out there at my friend's, ...then I might come and touch her, and she might be having some nose bleeding, you see. That is how you get it. That is what I am afraid of. Mostly that, (Urban p. # 1-7).*

When I asked one other participant how she thought her caregiving responsibilities affected her health, she said:

*It once crossed my mind, that I might contract [something], not just AIDS, but TB....If God happens to make his judgment [i.e. take the life of the patient], I will go to the hospital to get tested for TB, me and the*



*children, since she [patient] has been living here for some time, (Urban p. # 11-1).*

Apart from the *fear* of contracting AIDS and TB, there is also a sense of her inability to change the situation (i.e. *powerlessness*). This comes across in the following statement: "If it so happens that the doctors find I have TB, I will just go for treatments, because to be seen refusing to look after your own mother's child because you are afraid, is not proper." Although there is *fear*, this participant vowed to continue looking after her sister right up to the very end.

The themes of *powerlessness* and *despair* come across very strongly in the following case of a participant who had to bathe a sister with sores from herpes zoster, twice a day. She said:

*We put that medicine [antiseptic] in the tub and wear gloves, but they are not easy for us to obtain these days. And you find that your hands are wet, yet you are wearing gloves! But there is nothing you can do, you see...because she no longer has any strength to bathe herself. Sometimes you feel grossed by it all, but [it is hard to give up] if the person fighting for life like that is your relative, (Urban p. # 12-2).*

The fact that this participant cannot afford a new pair of gloves is indicative of the utter sense of *deprivation*. Hence she has to use an old pair with holes that let in water, with the chance of exposing her hands to the AIDS virus. This signifies this participant's sense of *despair* and *powerlessness*, because she cannot alter the situation to her benefit.

Moreover, the fact that she is helping a relative transforms the dedication into a bond that she 'cannot' break. Apart from genuinely wanting her sister to get better, therefore, the fact that this participant said, "...we need information on what medication we can give her to boost her strength, especially to enable her to bathe herself..." might also be indicative of her desire to eliminate an imminent threat to her life. The participant's sense of *despair* was also generated by the patient's reaction to having someone bathing her wearing gloves:

*Moreover, the problem here is that the patient, okay we know there is this AIDS disease out there, but she was saying she doesn't have the disease. When her husband died they were no longer sleeping together, so she has always said she doesn't have the disease...But what we are seeing now is to the contrary. She used to refuse, even now, if you use gloves with her she thinks that you are loathing her ('Ukavashandisira magloves sooka, vanotoona setirikuvasema'), you see. That is the problem we are facing, (p. # 12-2).*



*handle children, persuading them, and talking to them using the soft approach, not with a raised voice, (p. # 11-1).*

Other caregivers and HBCW substantiated this position that PWHA have more anger in them than other patients. A particularly poignant example is that of an HIV+ caregiver, whose assertion is based on experiential knowledge both as a patient and caregiver. When I got to her house on one particular day, she had just been talking with members of her support group, contemplating visiting another member that was seriously ill, in order to help with some household chores. One other task on their agenda was "...seeing to it that she eats her food, because when some people are sick they do not want to eat," (Urban p. # 7-10). Speaking about this particular patient, she said, "Sometimes she gets angry with her children, so if we can persuade her to she might force herself to eat."

When I went further to ask this participant what she thought was the reason for patients to get angry with their caregivers she said:

*When a person gets ill, they just get angry, especially people that are HIV positive. They just get angry, all of them and most of the time. It's something that just happens when you are HIV positive. With some, it becomes very difficult to look after them, such that it requires a 'long heart' ('kana kumuchengeta chaiko zvinotoda futi moyo murefu'). [my emphasis]*

She went further to explain how she managed to control herself, or have a 'long heart', by saying:

*During times like now when I am conscious of what I am doing, I make an effort to control myself, because I know I mustn't give problems to those that look after me. But when I was sick myself, for example there is a time I lost consciousness that they closed my eyes [for dead], and regained it at Parirenyatwa Central Hospital. [Then] I used to get angry, to the extent of wanting to hit people, and yet I couldn't even get up.*

This participant's patient (i.e. husband) was said to be "...always angry [laughter]." Even though she "...tr[ied] to control [her]self..." if this "...persisted [she] also g[o]t angry as well [laughter]" (p. # 7-10).

Another participant that experienced the anger of her patient subsequently had the situation explained to her by a friend/peer helper. When I asked her to explain to me the problems she encountered and might need help with, she said: "During the times when she is in pain, she [i.e. sister] has a lot of anger in her. And I often wonder how that



comes about, and there is a time when this escalated into a fight, and I gave up looking after her," (Urban p. # 14-4). A friend of the participant that the patient asked to intercede on her behalf then carried the ensuing conversation with the participant:

*"I would like to leave you with these thoughts. Know what? When a person is sick, especially with this type of disease, they need a caregiver with a 'long heart.'" And I asked her why she was saying this, and she went on to say, "My brother once got sick, and I always couldn't understand what was going on." ... So I learnt a lot from this... (p. # 14-4)*

Despite the call for a 'long heart', this participant sometimes reacted to her patient's belligerence in the same manner as participant 7-10 above. She said:

*Since I am also a human being, made of flesh and blood, sometimes I also raise my voice [laughter]. Sometimes you also wake up behaving as if you are possessed. For sure I do that sometimes, but for the most part I forgive very easily, (p. # 14-4).*

Another participant that received advice on this issue from a friend/peer helper said:

*She [i.e. friend] would just say, "...it's difficult to look after a patient. You have to have a 'clean/white heart' ('ende unofanirwa kutochena moyo'), ...not to panic...So my friend, you have to have a 'clean/white heart', [because] these people [with AIDS] are troublesome, and they say a lot of nasty things..." (Urban p. # 3-4). [My emphasis]*

Maintaining one's composure and being able to forgive seems to be difficult for most caregivers, because, like participant 14-4 above, the following participant seemed to go toe to toe with her patient. She said:

*This patient of ours has a foul mouth [laughs], and if you are not a relative like that, you ask yourself, 'What am I suffering for?' ...But when you are a relative like this, you just wash it away. When she shouts at you, you can just shout back, and it ends there, (Urban p. # 12-2).*

While this might be easy with a sister as is the case here, with a participant looking after a mother, cultural dictates prescribe differently. She said, "I don't usually answer back...it is up to you to realise that you shouldn't answer a sick person back...I just keep quiet," (Rural p. # 8-1).

The sub-theme concerning PWHA being more verbally abusive than other patients was echoed by one HBCW who said that patients have "...anger in them" also said that these patients usually "...do not like the patients in the home," (p. # HBCW1). She went further to say that the moment a HBCW walked into a home, the patients "...lighten up and begin talking to you." With the HBCW on their side, patients begin telling them:



*"They are not giving me 'sadza' [in a whisper, mimicking a patient telling a secret]. They are saying this and that about me..." But you know that they do give him/her [laughter]. "They are cruel, the way they treat me! Yesterday they beat me up..." Or you hear, "I have not been given 'sadza' because I am messing up my bed,"* (p. # HBCW1).

According to this participant's account, patients are eager to have time with HBCW when they visit. This might be indicative of the tension existing between patient and caregiver, and when HBCW come, the patient might be inclined to embellish the truth in order to have someone on their side.

When I asked this participant what she thought brought this anger she gave a very plausible explanation:

*They [i.e. PWHA] have a lot of anger in them. I don't know where that anger comes from. Maybe they haven't yet accepted the fact that they are sick. So they are looking for someone to blame. Or maybe they think, 'I used to walk on my own [not too long ago], now I have to be helped by someone, and get a bath from someone...', and that makes them angry. So the nearest person to them becomes victim to that anger [laughter],* (p. # HBCW1).

She went on to give the example of a young man that had recently passed away, whom she said used to be pompous, and found it easy to pass disparaging remarks about, or laugh at other people in public. The young man's condition deteriorated extraordinarily fast, and he showed his anger when visited by outreach workers. She then went on to say,

*Surely, something like that is bound to make one angry. Because he used to stand outside their yard there, making fun of other people. And today it has come your way, surely that is bound to make you angry.*

She also said that when people start "...wonder[ing] where [one] got the disease from...that makes [one] angry and [they] start to shout at others [laughter]."

Therefore, generally we might say the anger has to do with one's inability to come to terms with their illness and not accepting reality, questions to do with why one let themselves catch AIDS, what they think people around are thinking about them. Whatever the cause, the effect is the immeasurable dents daily imprinted on the caregiver's ego. It tests one's patience, and makes caregiving a burden one has to bear because there is no ready solution to the problem.



## The Burden of Deprivation: Bearing it

While I have discussed poverty in the previous chapter, the focus then was the objective condition. At this point I am more interested in the actual experiences of caregiving under such circumstances. Every one of the participants in this study had the gravity of deprivation pulling down on their *lifeworld*. While the magnitude of deprivation relatively differed between participants, all experienced difficulties providing the basic necessities (i.e. food and clothing) for the patient and the family, as well as money to purchase health care services. I have already discussed the participants' experiences with food shortages above, and will therefore leave it out here. Some participants conducted their caregiving duties under appalling living conditions, and this was of great concern to them. It is these burdens that caregivers had to *bear*, without any prospect of abatement in the foreseeable future, and the state of affairs cannot be described as anything but *desperate*.

One particular urban participant managed to make a comprehensive and passionate touch on most of the aspects of deprivation described above. The patient had no other source of income but her husband's pension and rent from a tenant; and the caregiver mentioned that the patient's condition took a turn for the worse, "...because they could not find any money [for medical treatments since the] tenant delayed giving her rent..." (Urban p. # 12-2). Therefore, the patient "...went for some time, about two weeks, staying in the house without any medication for her sores..." Speaking about the state of inflation and the family's financial situation she said:

*These days if you get any money, it has the tendency to 'fly away', and sometimes illness comes into the family when you have nothing left for medical treatments .... In order to look after her, all I need is money, because these days life is moving on the wheels of money; because for you to go to the hospital, you need money, the soap you use to wash clothes for the patient needs money, the food you give the patient needs money, that is our only major problem. For one to be said to be looking after a patient well, you have to have money within your reach. Without money there is no way you can look after a patient properly, because you have nothing to cook for them, you have nothing to bathe them with, and you don't even have a good place to care for them, you see (p. # 12-2).*



This sentiment about money being the solution to their omnifarious needs was echoed by another participant when I asked her what worried her the most, of all her caregiving problems:

*Money is the problem. You know, everything is money, money, money. You end up thinking, 'If I had my own money, lots of it, problems wouldn't be pressing me down like this, (Urban p. # 5-6).*

Certainly, this was a concern weighing heavy on every caregiver's mind.

At the time of the interview with participant 12-2 above, their rent and electricity bills had not been paid, and the participant showed deep concern. She said, "And it is doubtful we will be able to pay double next month. If we are going to pay double, that is going to mean we do not have money for food..." Also, apart from not being able to buy tablets for the patient's illness, the participant said:

*We would have wanted to send her for TB tests at the Infectious Diseases Hospital ['Nazareta'], but we have no means of transporting her there. And the X-Rays require money as well. We cannot foot the bill hundred percent.*

At the back of this participant's mind is also the knowledge that other PWHA "...survive longer, even after getting to this [bedridden] stage, if they undergo a TB treatment cycle," which makes her inability to pay for the X-Rays and transport to the hospital a considerable burden on her mind; because that "...might help prolong her [i.e. patient] life to the extent whereby she might leave her children a little bit grown up and in a better position," (p. # 12-2). The *desperate* nature of the situation is evidenced by the fact that:

*There came a time when we thought of selling household items, thinking, if we sold this item [VCR], we might get something. But with the current state of the economic situation, things don't necessarily get bought during that time you want them bought. That is the problem. The wish that if I could get money is there, but there is nowhere to get it. That is why the white people came up with the saying, 'If wishes were horses, beggars would ride,' [laughter]; but there is no way out. Things are tough, (p. # 12-2).*

Therefore, lack of money when one needs it sends one into a state of desperation.

Another participant echoed the sentiments of this participant and many others, regarding the fact that illness episodes often encroach upon the patient when the caregiver has no money:



*It's like those times, like now, when I do not have any money on me, right? I don't know how these things happen, that mother or my sister gets seriously ill in just a few minutes, when I don't expect it, right? So, these scenarios are some of the things that make me realise the importance of having money that I can call my own, so that if anything should happen I know what immediate course of action to take, (Urban p. # 14-4).*

*Sacrifices* are the order of the day in the face of *deprivation*. For example, when I asked an urban female participant that was thankful for free TB treatments if they would manage to pay for these treatments in the event of the subsidies being withdrawn, she said:

*We would have to struggle. Even this little we are getting from his [husband's] employers, we would have to sacrifice and do without food in order that he gets treatments so that he can go back to work. Because if we put food first, he is the plough that provides for the family, so we cannot afford to let it die, (Urban p. # 13-3).*

Although this was a hypothetical question/scenario, sacrifices were part and parcel of the daily lives of caregivers. Scarcity of resources meant a lot of juggling, satisfying the most immediate needs. Another participant with two patients (i.e. daughter and son) indicated that the support she got from relatives was not enough to meet the basic needs of her patients, such that she would have to *scrounge* around to meet the vast amount of the other needs, "...just so I can get something for my daughter and son to eat," (Urban p. # 5-6). She also described how she sacrificed money she got from tenants in order to feed her patients:

*Also, I am having difficulties paying rent [for the house], because sometimes I take part of the money for rent [from tenants in shacks and one inside room] so that I can buy things for the patients, afraid that my children might collapse from hunger, because there is no one formally employed that I can depend on [for an income].*

Similar grave concerns were expressed by another urban participant who was also looking after two patients, and also dependent for a living on rent from tenants. Apart from getting stressed out by the demands of the patients she could not meet, she also went on to articulate the depths of her desperate attempts to fend for her patients and two baby twins, risking losing her dignity in her neighbourhood in the process:

*This house costs quite a bit, in rent and electricity. So what's left over from the rent the tenants pay is very little after paying those bills. It's not even enough to buy food for a week. It's very little, you see. Therefore,*



*we survive on scrounging around, asking from others [i.e. neighbours]. Even if someone agrees for me to pay back by doing some work for her/him; I am willing to do that. Sometimes I ask people if I can do their washing for them, and they give me whatever they give me, so that I get something to help myself with, either buying a 2 kg packet of corn meal, so that I can cook 'sadza' or porridge for the patients, (p. # 3-4).*

The day I went for my second interview, I found this participant working in the garden of her neighbours, for a 'little something' in order to support her family. This kind of *desperation* that forces one to swallow their pride and ask neighbours resources in return for domestic/household tasks in order to cope, was also well expressed by a rural participant. During the times she happened not to have money for transportation to the hospital, she would go to someone with a car and say:

*My friend, I could always come back and do some work for you, or anything that needs to be done in your home, even weeding your fields, I am desperate... (p. # 7-1). [My emphasis]*

Also sacrificing time needed to work on their fields, she said, "We [also] go to nearby farms there to work [i.e. seasonal employment], and sometimes you can make \$100 or \$80 per month [i.e. US\$1.50]."

Most participants expressed their concerns regarding the poor standard of hygienic conditions surrounding their patients, particularly their inability to wash patients' blankets and clothes regularly, because they could not afford to buy soap. This participant had a better description of her situation:

*If I happen to wash them [i.e. blankets], say today, I spend maybe the whole month before I wash them again. They would have to stay like that [i.e. dirty]. If I manage to find some soap, then I wash them, but if I can't find it, they will have to remain like that. But if I see that it's too much, I just soak them in water, just to get rid of the dust, (Urban p. # 4-5).*

Whenever she had some money on her, she would buy some painkillers for her two patients, "That is how people survive these days, isn't it?" she said. She went on to say:

*[But] if I do not have money, they just spend the night in pain, while I sit and look at them. I just give them water to drink, and I spend the whole night seated...not knowing what to do, (p. # 4-5).*

What I sought to do here is present situations surrounding participants' caregiving situations that portray their state of *deprivation*, and how they experienced those situations. Participants had to *bear* with a lot of hardships, and a profound sense of



*desperation and helplessness* was portrayed in the discourse with almost each and every participant.

### Reaction to Caregiving Burden: 'Losing it' or Non-caring?

All participants in this study appeared to me to be very sincere about their caregiving experiences, particularly their dedication to help a 'relative', sister, brother or daughter. While the experiences of deprivation, stress, and all the other experiences discussed above were felt to be genuine and objective experiences, two cases put a dent in my belief that all participants wholeheartedly *cared* for their patients.

The first case concerns an urban male caregiver that was looking after a younger sister. When consent was sought at the very beginning of the study, all participants were notified they would be given gloves, a disinfectant, and some cash, to thank them for their participation. However, participants were told that these things were to go towards helping with the patient(s)' basic needs, and in some cases the patient was present during this initial discussion, as was the case with this participant. At the end of the last interview, these conditions were fulfilled.

A couple of weeks later, during the time to round up things and ask a few final questions, I did not find this participant at home, but the patient. Before I could sit down as is customarily expected of a stranger coming into a home, she went straight into a tirade about how the brother (i.e. the caregiver) had used up all the money (ZW\$500) that I had given him and never bought anything for her, despite the fact that there was no food in the house.

The story was that, the very day I gave him the money, he bought 'a lot of beer' (a plastic bagful) for himself. She raved on about him not caring for her any single bit. He was then cooking separately, because he could afford to buy better food for himself, though temporarily. Upon being asked by the patient, the participant had even declined he ever received any money from me. With his insensitivity, he had misrepresented the facts and told her that I had told him that his sister had AIDS, yet it was him that referred to her HIV serostatus on numerous occasions during our interviews. Upon his return, the two almost fought in my presence when he failed to substantiate his facts. In my presence, he denied all charges, but still couldn't explain why he used up all the money.



Irked by the brother's unrepentant behaviour, the patient begged me for money for there was nothing to cook in the home.

My second case is that of a rural female participant who, throughout our interviews spoke passionately about how she cared for her sister, and the sacrifices she was making, time and resource wise. Yet, when I cross checked with my informant, who was the local HBCW, it emerged that the caregiver was always reproaching the patient, even in the presence of the HBCW. The HBCW said whenever the patient asked for bath water, she was told, "You are bothering me! You are disturbing me from doing my work! Where do you think I will get the money for you to eat that kind of food?"

The most telling incident, however, happened a day before my last visit to this village. The HBCW had gone to the participant's house to check on the patient, and was told the patient had spent the day well. When the patient came out of the house to join the two, the HBCW asked her if she had eaten, but the caregiver answered instead, saying the patient was refusing to eat, and '...do I have to force her to eat?' The HBCW ignored that and went on to ask the patient if her condition was getting better, given the tablets she was taking, to which she said things were changing. This was when the conversation took a turn for the worst:

*That is when the sister reproached her, saying, "You are lying. Why don't you tell the truth? At night, instead of going to sleep, you spend the night making noise for us. And you go ahead and say you are not in pain? All that vomiting, isn't that pain? Why do you tell lies?" (p. # HBCW4).*

Not wanting this to escalate into anything more serious, the HBCW asked the caregiver to calm down and have a 'long heart', because "...when a person is sick their brains transform, they are not like any other normal person..." To this, the caregiver retorted:

*"I won't do that! I don't care about her myself! How many things should I do? On the one hand I clean her faeces, right now her panties in the house there are full of faeces! And her child has messed up herself up, and that has to be cleaned by me. My own child has also messed herself up, and needs to be cleaned up by me. Altogether I have to clean up the mess of three people! What benefit do I get from doing all that! I am falling behind with the work on my fields, because of the constant care I have to give to her. Better to leave her. I am going to the garden right now, I am leaving her [alone]," (p. # HBCW4).*



The gist of this lament about job overload sounded all too familiar to me, minus the diatribe. During my interviews with the participant, she had couched her complaints about lack of time and role conflicts in the necessary obligation to help kin.

At this juncture, with the participant's announcement that she was going to the garden, the patient had asked to go and while up time at the HBCW's home. The HBCW gave her indication that this was okay with her, but according to the HBCW, the cantankerous caregiver retorted with even more fury:

*"Sit down right now, quickly! Where do you want to go? You have a child that is defecating everywhere, you want her to go and defecate at other people's house?" And I implored her to let her come with me. Apparently the child was dirty then, she had just messed herself up, you see. And I pleaded, 'Please don't do that. Even if the child messes herself up at my house I can clean up. Isn't it she [i.e. the patient] wants to stretch her legs? Sitting down in one place for a long time is not good for her...' (p. # HBCW4).*

Due to the caregivers' uncompromising position, the patient gave up, picked up her child and took her inside the house to change her. The HBCW's opinion was, "She is not understanding that woman."

While this caregiver's behaviour might have been basically due to her nature, it might also be interpreted as a result of the pressure from the caregiving burden. That is, the stresses, inability to cope with deprivation amidst multiplying demands for resources, the role conflicts and role overload, might all have culminated into a burden that exerted immeasurable pressure on her such that she just 'lost it'.

### **Social Reactions to AIDS, PWHA and Caregiving**

Both the people infected and affected (e.g. caregivers and other family members) with HIV/AIDS react to the disease in different ways. Kin and the local community also react to the disease in different, and unpredictable ways. Most of the reactions contribute towards the stigmatisation and discrimination of those infected and affected with HIV/AIDS. PWHA and their caregivers, in turn, react to the felt and enacted stigma and discrimination; that is, they react to the reactions of other people. The main contexts of stigmatisation and discrimination that I will focus on are: the legislative, and family and



immediate community. This section is partly ethnographic, in as much as it describes social reactions, and phenomenological, in as much as it deals with the way caregivers experience stigma and discrimination. It also focuses on the interface between caregivers and PWHA, depicted by the two Venn diagrams in *Figure 2*, and the community and government contexts above them.

## **Types of Social Reactions to AIDS: An Ethnography of Stigmatisation and Discrimination**

### Health Service Contexts<sup>9</sup>

This reflects stigma that results from AIDS patients being discharged from hospital because of the incurable nature of the disease. Due to the astronomical costs of treating PWHA, the government of Zimbabwe's health sector initiated the home-based care programme in order that patients be looked after at home by family members, with the assistance of home-based care workers (Ministry of Health and Child Welfare, 1996; Woelk et al., 1997). Due to the astronomical operational costs of the formal home-based care programme, however, it has been difficult to sustain it for the benefit of family caregivers and their patients. This strategy, has been dubbed "home-based dumping", has taken centre stage, whereby "...people find themselves turned into nurses over night without any resources or pre-counselling."<sup>10</sup> It is the caregivers' perceptions of their patients being ignored or discriminated by the government that can allow us to take this as a process that contributes to the overall stigma attached to the disease. Caregivers tend to think that their loved ones are being thought of as not worth helping, that a death sentence has been passed well in advance.

According to one HBCW, her superiors "...decided to recruit [more] women from the community to help..." the home-based care team from Mashambanzou Palliative Centre, because, " most patients that visit hospitals are being turned back, to receive care in their homes," (p. # HBCW1). The plight of low-income people is captured in an incident described by this HBCW, whereby a patient was taken by his family members to:

*Parirenyatwa Central Hospital, and they were told to go to [the Infectious Diseases Hospital] 'Nazareta', where [they] were told to go to*



*Harare Central Hospital. At Harare Hospital they were told...[to] go and buy tablets... [But] they said 'we do not have the money.'*

This family came to the HBCW hoping she could get them some tablets from Mashambanzou Palliative Centre for free. This HBCW's sentiments regarding her sense of abandonment of PWHA by the government go as follows:

*And if you take someone to the hospital, they get discharged the following day, in the same state. Therefore the government should intervene. This disease is not an individual problem ['hachizichirwere chemunhuka ichi'], it is everyone's problem. So we wish the government could come into the picture, showing its presents in clinics, hospitals, and homes, (p. # HBCW1).*

However, the sense of abandonment is more vividly felt and expressed by caregivers, because they are the ones that are at the direct receiving end of this policy. One participant that had a bedridden patient that got discharged in the same state (that she took her into a local government hospital) on several occasions had this to say:

*Mostly, I blame the hospital ['chikurukuru ndinoshora chipatara'], because they send a seriously ill person home. I have no medical knowledge and I don't know what is supposed to be done to the patient. If only they could at least admit her, then make sure that the situation is better, and then give her back to us. For example the day she was discharged last Tuesday, [name] she came out vomiting seriously. And I asked them, "You are handing her over to me when she is vomiting like this, what do you want me to go and do with her at home?" And they said that there was nothing they could do...the doctor had said she should be taken home. And for sure I brought her [name] while she was vomiting like that. And that was difficult for me. I did not see any change, until I went back the day before yesterday, but they said the same thing, that [name] needed to be looked after at home, by you her relatives.... So, I wish they would come to a point where they could say okay, things have reached a critical stage and the situation warrants the attention of those trained to handle it (Urban p. # 11-1).*

This sense of being stigmatised and discriminated against is all the more poignant when this participant compares the above-described government hospital to a private hospital where the family eventually took the patient:

*[Right] now I have gone to the hospital where she is now, and if I compare that with ... [name of hospital], it's like they were even afraid to give her more blood, because she had this particular disease. So, they were now seeing her as if she was no longer a person deserving help. And they would say, "There is nothing else we can help you with. We will just put her on intravenous, and you take her back home." But here*



*we have seen that they are really trying everything ['asi apa tiri kuona kuti vari kumhanyamhanya']. They have given her blood, they have put her on intravenous, and they have done this and that. Even where she is sleeping, it's not a boring place. You can clearly see that they are handling her well, and we don't have any ill feelings (p. # 11-1).*

When I asked this participant what kind of support she would want from either organisations, relatives or friends, her experience with this government hospital overshadowed all she might have wanted from relatives or friends:

*Yes, there are times when I wish I could get help. There are situations that we experience on a day-to-day basis, and then sometimes you see her vomiting non-stop...and she has diarrhoea non-stop. And you can see that she is tired, she has no more strength. For sure when things get to that stage I need support. I wish they could give her some help so that we get relief. But if I take her there [hospital], they just put her on intravenous and tell us to go back home with her....So you just see...I don't know how I can say it. Maybe they think that people with this disease are not supposed to receive treatment....What if she lives four more years from now, from today? ...But one would have already passed their judgment, that this person has no life left ['kuti aa ndofunga hapana kwaachasvika']. But no, they must just do their work the way they are supposed to do it...[until] God passes his judgment...Not for them to say, "This person will no longer be treated, because they have a particular disease". That is what I noticed at ...Hospital (p. # 11-1).*

The strategy to send AIDS patients home, which leads to the aforementioned perceptions of being discriminated among caregivers and PWHA, seems an untoward repudiation of the government's obligation to uphold its policy of 'Health for All' and its equity principle. According to this participant, and many more, the government passes judgment on PHWA, while they favour people with other diseases. This perceived sense of being discriminated is depicted by arrow labelled '(a) early discharge', running from the square labelled 'Government' to the circle labelled 'PWHA' in *Figure 2*.

### Family and Immediate Community Context

This context comprises of close kin, friends, neighbours, and general community members. Their reactions to AIDS, the PWHA, and their caregivers are as varied as the individual experiences, but fall into these general categories: generation of gossip and rumours about the PWHA, loathing of PWHA, isolation, shunning and ostracism of both infected and affected, and withholding support for affected family members.



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*Gossip and Rumours: The foundation and fuel of stigmatisation:-* All participants acknowledged that they had heard some rumour of some sort about the disease their patient was supposedly suffering from. First of all, people rely on their '*lay diagnosis*' to determine what one is suffering from. One 'sure' sign of AIDS is a prolonged illness that does not seem to go away. Traditionally, it is believed that a protracted illness is a sure sign that it is not a natural illness, or one from God, but one with supernatural explanations. With these kinds of illnesses, consultation with traditional healers and recommended reparations, either to the ancestral spirits, or an aggrieved person that jinxed you, should see the illness go away. Those that witness all these efforts to no avail, immediately make conclusions, while other do make them without being witness to any ceremonies or consultations within Western or traditional medical systems.

Other visible signs include wasting away, a darkened complexion, having TB, and the hair loses texture and becomes thin and straight. While these are some of the visible signs that people look for, it is also true that other diseases can manifest themselves in the same manner. But what is important here is what people believe it to be, and how they subsequently react to it. According to one urban participant, "...AIDS can easily be recognised, losing weight... skin diseases, and your health is not all that good" (p. # 12-2). All participants that talked about rumours indicated that it is the people that come in the pretext of seeing the patient who subsequently go out to gossip. After someone has visited:

*You hear that they are saying, "Ahh, it just must be it [AIDS], what type of an illness is it that is not treatable?" So, someone has already deduced that it is AIDS, and yet they have come and seen the patient sleeping... (p. # 11-1).*

More often than not, people that visit to see the patient "...go and tell someone close to you..." and "...they say more than they saw. Whatever they have seen, they go and add on whatever they want..." (Urban p. # 6-12). This issue of embellishing the truth was a concern expressed by all participants who talked about this issue. According to one participant, people are finding it easy to go around spreading these rumours, "Because these days even if you scratch a sore ('ukangokwenya mhezi'), people think it is 'it' [i.e. AIDS]," (p. # 3-1). Also, when one is suffering from TB people 'start talking'. One urban participant said, "...some are already talking, for example, with regards to this TB, you



see the conclusions they immediately rush to make. They will be saying it is AIDS...but they won't say it openly..." (p. # 3-4).

Most participants said that rumours were mostly started by relatives and friends.

*Relatives are the ones that spread the rumour that one is sick, "He/she has the AIDS disease...Have you seen the way he/she looks? He can't even get up now. He/she can't even do this and that. And the stench that comes from the room!"...Relatives come and say a lot of rubbish, without giving any support or anything but degrading talk, (p. # HBCW5).*

In all cases, the affected people get to hear about these rumours from other people that they get along with. Speaking about her uncle that was spreading rumours about her mother, one participant said, "I think this was caused by the hatred between us, because we do not get along with them," (p. # 5-1). But even good friends, "...are the same people that destroy you, by going around telling people that there is an illness there, and so forth, " (Urban p. # 4-5).

Rumours also start from positive steps people do to take care of themselves. For example, when one participant went to register with a local support group, this served to confirm people's suspicions and rumours that had been circulating:

*During the days we registered at the [name], a lot of rumour circulated, going, "You see, those people with AIDS are now going to register their AIDS status....So that rumour circulated for quite some time, that I had gone to register...(Rural p. # 6-1).*

This participant suspected that some other people she met when she went to register might have started the rumour.

Whenever rumour spreads, other people get curious and come to see for themselves. Whenever people visited this participant, they would ask what her husband was suffering from, and she would tell them "...he feels pain all over his body...". However, because they would have come to satisfy their curiosity, they would ask:

*"The AIDS that we often hear about, that he has AIDS, does it attack legs like this?..." "Is it AIDS causing pain just in his legs?" "How come the face indicates that the person is healthy...? Is that what AIDS does, attacking just the legs?" (p. # 6-1).*

An interesting case is that of a couple that publicised their serostatus, and neighbours spread vicious rumours about the TB they were suffering from. At the time I went for my study, the couple was in good books with the neighbours:



*But now they also have TB and are also taking TB medication. We get along now, but I cannot say to them, "What were you saying those days? Look, now you are facing the same problem." So we are now getting along well, (Urban p. # 7-10).*

Apart from affecting the image of the person rumoured about, rumours and gossip have the tendency to escalate into conflicts between neighbours, because of the stigma surrounding AIDS. One rural female participant described of a scenario whereby interaction with local married male folk became almost impossible:

*What happens is that someone might come here, like right now. Isn't it you came and parked your car? And neighbours will be going, "Ah, you saw the car that was there? Doesn't he know that the women there have AIDS? [Animated] They have AIDS those women! He is going to die, from that AIDS! That girl he has come to see has AIDS!" You see. Sometimes you just happen to be passing by someone's house, and someone happily greets you, "How are you, how are you?" ['makadii? makadii?'] And then later, that person's wife passes by our yard, shouting, "If I happen to die! ...So if I die, I just know that I died from their AIDS...['nenhingiriki']. They are shouting as they pass by. She would have been told by other people, (Rural p. # 7-1).*

Gossip and rumours also fuel the stigmatisation that results in the social isolation of those affected. For example, the same participant indicated that she had on several occasions heard the disparaging remarks made by her friends:

*One might say, "I think we are going to be given bad diseases, things are not okay at that home ('isu tichatoparangiwa'). Even eating anything from there? Ah, no. Even receiving anything from that home? Ah, no, otherwise you will be given a disease, ('unongoparangiwa hoshia')." Sometimes you hear about these things from elsewhere, because they won't say that in your face, (Rural p. # 7-1).*

Rumours and gossip by neighbours were also found to break ties with friends, as well as interfere with one participant's livelihood. According to this participant:

*You just hear rumours that people are saying there is an illness here, that tenants must go; otherwise they will contact the disease. That is why you see there is nobody in that room. [another day] These neighbours tell my lodgers, within my earshot... Sometimes they call out, "Come here. What have you come for there? You will die, there is a dangerous disease there..." And before the month is over, you hear the tenant saying, "I am going, give me back my money,"(Urban p. # 4-5).*

Because of these vicious rumours from her next-door neighbours that scared tenants away, this participant had her livelihood threatened. Her friends were also kept away by



the rumours, because the "...rumours on the streets [were]...scaring people from coming here, lest they get diseases" (p. # 4-5). This reaction to AIDS or PWHA is represented by arrow 'b' in *Figure 2*.

*Loathing*:- Another very clear theme that emerged from the study was that friends, kin and other community members regarded PWHA as disgusting. This reaction is represented by arrow 'c' in *Figure 1*. According to most participants, this reaction goes hand in hand with fear of catching AIDS. Loathing is not confined to other people only, but is a reaction common among caregivers too. Since they would not say it themselves, an insight into this phenomenon was gleaned from an HBCW that was reporting on her experience with some of the encounters between caregivers and patients.

*Plus being loathed, 'They think that I might spread the disease to them. They are suspecting that I have this 'new disease.' That is what the patient says, (p. # HBCW4).*

Answering my question whether there were any relatives standing aloof, in terms of assisting with caregiving, one female, urban participant said:

*Yes, you can easily see that one is grossed by the mess ['unongoona kuti munhu arikusema'], because...what they do is, we have chairs and maybe there is three or four of us, when they come in here they remain seated, and yet some of us are already by the bed, giving attention to the patient. So, you can clearly see those with love, in the way they support wholeheartedly...[later] Some are afraid that they will contract this disease, that is the largest number, and you can sense it when you talk to them.... And one might ask, "So, how are you handling things [name of participant]? Don't you think you might end up contracting the disease?" And you can read one's mind right there, that they are afraid they might contract the disease, and so they will not be able to help me, (p. # 11-1).*

Some people actually choose what chores to help with and which ones to avoid, depending on how they perceive the threat of catching AIDS comes from.

*[Y]ou cannot look forward to someone coming to help you with household chores or washing. These days it is difficult, because some will be afraid the patient might be suffering from this disease or that disease, and they keep away...Maybe they might choose to come and wash plates, or wash the children's clothes, not anything to do with the patient; these days it is not common, (Urban, p. # 13-3).*

For a sister that could not bathe her own brother, asking friends to do it for her was non-starter, because, "...they are afraid they will contract the disease...people are [simply] not interested," (Urban p. # 3-4).



Some family members openly go around expressing their detestation. For example, family members (father and mother-in law, brother and sister-in law) of one female participant would go about openly saying, "...People with AIDS are now boring to look at, we don't want to see them. If there was any place to send them we would have told them to go and stay there," (Rural p. # 6-1). Being 'stigmatised and loathed...', together with the patient, were some of the major problems faced by this participant.

Loathing also results in diminished close contact. In the case of an HIV+ couple (participant and patient), the behaviour of the husband's brother was more telling:

*[W]hen he comes, he does not even get out of the car. He stays in the car, and you have to go see him outside there and he goes back, (Urban p. # 7-10).*

Diminished contact also means refusal to shake suspected or known PWHA's hands, especially during greetings. This is a very conspicuously negative reaction, because shaking hands is an important aspect of the greeting process in *Shona* custom.

*Some people think that they can contract the disease through turning a bedridden patient, changing their clothes, etc... That is why we give them gloves... As for that one we have just visited, we can say that is full blown AIDS that he has got, but people like me are said to be living with the virus. I don't believe that if I greet someone by shaking their hands like this they would contract it from me. But now, many people refuse. As for me, they refuse to greet me [by shaking hands], because I publicised my serostatus, (p. # HBCW4).*

According to another rural HBCW this:

*[H]appens because of ignorance. What I think is, loathing and not greeting ('kusema kuya nekusamhoresa') are a result of ignorance. Those people don't have the knowledge on the nature of transmission of the disease. Up to now there is still a lot of ignorance in these villages... That spirit of fearing to greet someone with AIDS, or getting into their home, is still prevalent...in many places, (p. # HBCW5).*

Loathing of PWHA and their caregivers also extends to feelings of disgust for anything to do with these people, most importantly food prepared in their home. Sharing food is one common aspect of *Shona* traditional culture. However, the advent of AIDS, and the ignorance surrounding how it is transmitted, has brought forth a new dimension to this support resource.

*You see...sometimes we cook some food. We have these next-door neighbours, so we invite them, "Girls, we have cooked some food here, please come and eat!" And they go, "Oh no girls, no, no, no, we have*



*already eaten, for sure!" And you go, "How come we used to exchange things before?" ('Ingawani kudhara ndaikumbirana naye?') I can say, those days when she is seriously sick, people won't feel that much free in our house....They think that...they may get it through that food... [S]ometimes what happens is, while she [patient] is seated like this, she releases some waters [urine?]. Just releasing some waters... ('dzobuda kuti chakwa, haazogona kuzvita control') she can't control herself, you see. We might be just seated there, talking...And they go, "Eh, eh, eh, eating things from that house? Maybe...the wind might just come and blow...into those things you are eating, and you contract that virus."... But these days some people are beginning to understand a little, (Rural p. # 7-1).*

Sometimes the loathing affects one to the extent that one begins to pine for even the minute interactive processes that existed before the disease. The same participant, for example, said that:

*[Y]ou might go for a year...and no one comes to say to you, "My friend, do you have any sugar [I can borrow]?" No one ever comes to ask you....They used to come to ask for things...I don't know what they are thinking, but I suspect they are afraid if they ask for things...they will get [the disease] through that food, (p. # 7-1).*

Some participants also contended that hospital personnel also loathed their patients. At the time of the study, nurses working in most government clinics and hospitals were on strike, and the one of the grievances was infectious diseases allowances. This includes AIDS, which they came into contact with on a daily basis. However, loathing, on the part of health personnel, resulted in sub-optimal care for PWHA. One particular participant said that taking a patient with AIDS to her local government hospital was only a result of lack of alternatives, and, "...all the times they discharge her I feel relieved ('ndinonzwa kusununguka'), because I am sure that at all times ...[name] is sleeping on clean and dry linen," (Urban p. # 11-1). These were her particular observations whenever she visited her patient on several occasions during the three times she was hospitalised:

*[Y]ou could go there and get told that she messed herself up to four times, and they hadn't changed her. Sometimes you could see her urine reaching as far as the back of her head, and they are not changing her. So, what does that mean to a patient? They will be loathing her obviously ('Vanenge vachiita kanenge kakusema, eheh'), yes, (Urban p. # 11-1). [My emphasis]*



According to this participant, early discharges and lack of proper care were a direct result of loathing.

*I see that the elements of repugnance ('kakusema') and fear for one's life are increasingly taking control, making people indifferent towards us...[My emphasis]*

Loathing is therefore perceived to be a reaction common among both professionals and lay people. Most importantly, however, is the fact that this fear and loathing, on the part of lay people, particularly among kin, friends and neighbours, lead to other equally damning reactions, such as, shunning, and ostracism.

*Shunning : PWHA and caregivers 'out in the cold':-* To shun is "to intentionally avoid or keep away from someone or something," (Chambers 21<sup>st</sup> Century Dictionary, 1999: 1300). Apart from loathing, shunning was found to be a very widespread reaction to PWHA and their caregivers. In *Figure 2*, this reaction is represented by arrow 'd'. Kin, friends, and neighbours were perceived to be engaged in this behaviour. In most cases, shunning involved cutting off links with the affected people, or not visiting their home regularly, as would be expected under normal circumstances where there is a patient sick from any other disease. The moment "...you tell them that there is an illness, they do not show much interest in coming," Urban p. # 10-1). In some cases relatives have "...told their children not to [visit]...fearing that they would contract the AIDS," (Urban p. # 12-2).

According to the same participant, her patient's friends stopped visiting as soon as she became bedridden.

*My sister's friends used to come here when she was still able to walk. Right now we do not see any of the people she used to befriend. But when she used to walk on her own they used to come, "How have you spent the day? Etcetera..." You see. Right now, since she has become bedridden, no one is coming, (p. # 12-2).*

Another participant that was HIV+ herself said that friends and relatives were "...now refusing to have anything to do with [them]", and "they did not visit anymore," (p. # 7-10). She also said the following about her childhood friends:

*The ones we grew up with are nowhere to be seen, from the moment they realised that we are HIV positive...[And when they happen to run into each other on the streets] they just behave funny, such that you can clearly see that there is nothing in common to talk about. They just think*



*that maybe if we chat or something - especially if you happen to be struggling in life – they think you might ask them for help or something...maybe they think that they might contract the disease from us, I don't know, (Urban p. # 7-10).*

One participant that indicated that their relatives had become less supportive because they believed she was suffering from a disease she brought upon herself, also showed concern that most of their relatives "...can't even set their foot here," (Rural p. # 5-1). This participant's grandfather had three wives, who gave birth to ten male and five female children. All these uncles and aunts lived close the participant's home; with some living a stone throw away, but out of all these, "Only two" uncles and 'some' of the aunts used to visit her mother. According to this participant, this was not because they were afraid of being asked for support, but "...because she is sick from this disease," (p. # 5-1). The extent of the shunning was quite considerable, "[b]ecause, three months c[ould] go by before any of father's relatives sets their foot here to see how we are doing." Such shunning by close relatives made one participant to comment: "These days there is nothing like saying someone is close to you. Nothing like that anymore...[laughs]," (Urban p. # 5-6).

The theme of being shunned by relatives was confirmed by all discourses with HBCW. They were able to do so, because they are in close touch with realities in the local communities on a day-to-day basis. Moreover, some of them were HIV+, and were also speaking from experience. During my interview with one, she gave the example of a home we had just visited, where she had spoken to two sisters of a patient during my interview with the primary caregiver. They both told her it was impossible for each one of them to move into the patient's house in order to care for her, because they had their own homes, and children. Moreover, they said, "We also cannot take her to live with us because our husbands don't want us to do that," (p. # HBCW3). A HBCW that had personally experienced this shunning first hand because of her serostatus gave a poignant account that covered the gossiping that went on before and after she disclosed her status, as well as the distancing of relatives.

*As for myself that happened [i.e. rumours] right at the beginning, before I 'came out' in the open [i.e. disclosed serostatus]. People were just suspicious, saying. "Ummm, this woman has lost a lot of weight. This woman is really thin, have you seen her?" They would say this about both my husband and I, going, "No, it's better never to set foot at that*



house. " For sure, even relatives were no longer coming here; they would refuse to come here. And when we eventually 'came out', they started saying, "See, this is what we used to tell you. You thought we were lying when we used to tell you that these people are sick, you see ('Maifunga kuti tirikunyepa kuti vaavarwere vanhu ava, maona'), (p. # HBCW4). [My emphasis]

Even more than a year after the husband's death, the "...husband's younger brother...never sets foot..." at the deceased brother's house, and the participant believes the only reason is that they loathed her. Moreover:

*I have my father's older brother's child that lives in this village. I have never seen them setting foot here. But they used to come previously...I only see them when I run into them accidentally at Mutoko centre, when I go shopping...But they live in this village, quite near... (p. # HBCW4).*

Participants also often talked about neighbours, and how they shunned them and their patients. When things are okay and one is healthy, they come to visit, "But when one is sick...or they are beginning to mess themselves [in bed], ...sometimes they can just ask you," How has she slept today?" [Shouting] from their home," (Rural p. # 7-1). Shunning, therefore, is a common reaction towards AIDS, and those infected and affected by it. However, the effect of shunning is social isolation of PWHA and those around them.

Ostracism:- To ostracise means "to exclude someone from a group or society, to refuse to associate with them," (Chambers 21<sup>st</sup> Century Dictionary, 1999: 975). While shunning involves 'intentionally avoiding', ostracism involves excluding someone. The net effect might be the same, and the action might be the same (i.e. rejection). This is the reason I put 'ostracism' together with 'shunning' on arrow 'd' in *Figure 2*. By separating the two in this discussion, I intend to convey the message that ostracism means keeping someone at bay, away from oneself or one's group, while shunning means keeping away from someone. Ostracism was another strong theme in this study.

Ostracism is real and it is dreaded. PWHA and their caregivers can be ostracised by their relatives. However, there was one case whereby a caregiver was contemplating to do so. Although this participant said he was "...tempted to send [his sister] to go and stay at ...[name of palliative centre] because if he kept seeing her in her condition it would cause him great pain, the resultant effect would be the same, ostracism. Furthermore, this participant talked about his intentions, money permitting, to "...build



for her a shack behind the house there, so that everything for her would be done while she is out there." This would be necessary because there was to come "...a time when the illness shall become serious, such that one should not be too close to other people," (Urban p. # 1-7).

One rural participant that was looking after her sister expressed her uneasiness regarding what her in-laws might decide to do about her looking after her sick sister in her marital home.

*The way people talk, one might say, "Why are they staying with her here? They should have taken her to be looked after at their home." It is possible people might say such things, but I haven't experienced them. But it's in my mind, that there will reach a time when it will be mentioned, (p. # 1-1).*

Although this was just one's thought, based on experiential knowledge, other people affected with AIDS had actually experienced ostracism. One participant that went to Harare to seek medical help from a certain doctor she had heard "was helping people", contacted her brother so that she would go and sleep over at his home before taking the first bus back to Mutoko the following day. The brother gave several excuses, including the fact that he was only a lodger; there were a lot of people living in the house where he rented. However, her consultation finished early and she was able to catch a bus back home on the same day. But this is what she thought about that experience:

*I thought that maybe he thought if I slept there I would wash with his towels, or whatever... or maybe he thought I have a disease [i.e. AIDS].... I thought maybe he thought I have a disease and if I came and used his towels and other things, things would not go well for him after I left ('zvinozosara zvisiri kumuitira right') ...I realised that, although he didn't mention it, (Rural p. # 7-1).*

Ostracism can take much severe tones than the examples that I have so far given. It can involve having to ask someone infected or affected to relocate. Firstly there are cases of eviction once landlords know that someone has AIDS. According to one urban HBCW, some of their "...patients [we]re deeply concerned that if their landlord[s] happens...to know that they have AIDS, they w[ould] be evicted," (p. # HBCW3). Since most of their patients were lodgers, owing to their low-income status, this was a significant problem facing PWHA. One HIV+ participant living in a different suburb than the one serviced by the HBCW discussed above also said that accommodation was their



biggest problem. She said "...we live in constant fear of eviction since we are renting the room we live in," (p. # 7-10). She went further to cite a member of her support group that had recently been evicted by a landlord that had discovered they had AIDS. Her fear was not imaginary. Prior to coming to rent a room where she lived at the time of the interview, she had lived in a family home. After her father died, her mother had gone to live in their rural home, leaving a brother (from a different mother) in charge of the house. She was chased out of the house because of her serostatus.

*When I was living at my parents' house...my brother gave me a three days' notice to move out of the house. [That is when] I was taken into Masbambanzou Palliative Centre. He did not understand the nature of the disease then...By then he had given me my own cup and plate to use in the house (Urban p. # 7-10).*

Another participant (male) lived in a shack behind a family house owned by an absentee mother residing in her rural home. Despite the burden of looking after a toddler and a sick baby, the mother had intentions of moving them out of the family property.

Rural participants whose mother had died four months before, and were looking after a bedridden father that died three days after my last interview faced an even more severe case of eviction. They had lived on that land, owned by their grandfather (i.e. their father's mother's brother) since they were born, but things suddenly changed after the mother had died. They were told to go to their homeland, in a village about two kilometres away.<sup>11</sup>

*[T]hey have been saying we should move off their land since mother died...Right now [i.e. 2000 growing season] they are the ones that that are farming the field we used to farm, and we are left with nowhere to farm...It was when we brought father here [from Harare] that they told us to carry him to our homeland, (Rural p. # 2-1M & F).*

Five participants (three rural and two urban) in the study were looking after female patients that had been rejected, or sent away by their in-laws, after their husband's died. One rural participant said:

*A year after her [i.e. daughter] husband died, we went back to sort out the last funeral rights ('kogadzirisa zvemakuva'), and we were asked to take our daughter back with us. They had already noticed that the wife was already sick as well. So they said, "You better take your daughter with you, [since] there is no one that can look after her here. We have realised that she is sick," (Rural p. # 7-1).*



A HBCW, one of my rural chief informants, also fell victim to ostracism by her in-laws after her husband died of AIDS. She said, after she had given birth to her second daughter, the in-laws "...eventually told me I couldn't live there anymore, and that I should go back to my family home," (p. # HBCW5). Upon getting to her mother's and step father's home, she succumbed to TB and was hospitalised for two months, during which time her mother never visited her but went on spreading rumours about her.

*She never came to see me at the hospital. Then she started, my own mother, nobody else, "My daughter now has the disease that killed her husband, she is in her own room right now [i.e. quarantined]." That was my mother telling people...in the community...as soon as my sister came back to tell her I had been diagnosed with TB, (p. # HBCW5).*

Upon being discharged, this participant faced yet another experience of rejection.

*I never spent two weeks before my stepfather said to me, "Do you know that you are dying?" Those were his exact words. "And after you die, where are your children doing to live? Where do you leave them?" (p. # HBCW5)*

Eventually, the mother and stepfather took her and her children on a bus to leave them in her mother's rural home, where the stepfather said, "I am tired of looking after your granddaughter and her children. You can see she is sick now, and her illness is terminal ('hurwere hwake hauponese munhu')..." In turn, one of the grandmothers, in whose house she had been left, told her husband, "If you only accept her you are going to remain cooking for each other with your granddaughter [implying as husband and wife], because I am leaving." Confronted with a third experience of rejection, she carried her two daughters and walked several kilometres to Mutoko centre in search of 'hope'. This was an extreme and protracted experience of exclusion.

*Withdrawal and/or Lack of Support:-* Another social reaction to AIDS is withdrawal of, or lack of support provided to those infected and affected by the disease. Most participants believed that nowadays relatives and friends first of all would like to see what one is sick from before they help. If they should suspect that one is sick from AIDS, chances are greater that support will be withheld, because 'one brought it [AIDS] upon themselves'. Unlike diseases that 'just happen', or caused by God or malicious relatives or neighbours [through witchcraft], which people have sympathies for, AIDS is



believed to be a disease that one gets through prostitution. This was the general belief among most of the participants that were open enough about the seropositive status of their patients.

*It's just that this one [sister] got too excited with life ('akanyanyofarisa')... One of the days...I met her in town while I was with my friend. We had gone to a club, a sports bar in town... It was while we were in that club that I saw her [i.e. sister] wearing a jean, with some boys. She did not know we were in there. It really pained me, so I told my friend to go and tell her to go outside. Then I went and told her to go straight home. She had run away from home. It really pained me, even when I think about it today. I know where this person contracted this disease, because she was away from home for two months. Nobody knew where she was, you see, (Urban p. 1-7).*

In this society, going into pubs, clubs or bars is a man thing, and women that are seen to patronize these places are regarded as having loose morals. The same goes for wearing 'jeans' or any pants.

People that engage in prostitution are an already marginalized group, and "...the stigma attached to AIDS as an illness is layered upon pre-existing stigma" (Herek and Glunt, 1988: 887). The experience of one of my chief informants is particularly telling. Having married a person that was HIV+ but did not reveal their serostatus to her, a visit to a doctor with a pregnancy-related problem resulted in her getting tested for AIDS. On confronting the husband, who was already exhibiting symptoms of AIDS and "...c[ould] no longer do anything for himself," resulted in a verbal war in which he said to his foster parent, "...she must have been a prostitute, she is the one that gave me the disease..." (p. # HBCW5).

This double stigma can then be used as a basis for withholding support. A particularly telling example is that of a patient that was said to have led a wild life before settling in with someone that did not pay any bride price to her family. In *Shona* culture, this is called '*kubika mapoto*' (literally, cooking pots), which means, an 'illegal' union, or living together in a union not sanctioned by traditional norms and mores, something analogous to prostitution. Agreeing to the fact that relatives withhold support because of the nature of the disease, the caregiver (sister) of this patient said:

*That is exactly the case; they think she brought it upon herself. Because also, the way they were living here, it was like; no bride price had been paid to the in-laws, to signify marriage. She is someone that formerly*



*had an illegitimate child, that boy you saw. The father did not marry, but only paid damages. So, not having got married, she played around for a while [prostituting] ('munoziva, ndokubva vaakumbotamba dzenyika idzi'). Then she met these two young boys' father, and they started living together. That man was also quite libidinous/ promiscuous ('baba vachoo futi vakanga vasingabvirewo futi, ugh! Zvakanga zvakaoma'). So, it might be the case, that parents would say, "We didn't 'eat' anything from him." Yes, (Urban p. # 12-2).*

Therefore, the fact that the in-laws did not 'eat' (i.e. get anything in the form of bride price from the deceased live-in partner of this patient) was being used as a basis for withholding support. Also, the patient was seen as a person that deserved what she got.

Describing the lack of support from kin and friends, one female rural participant said:

*[W]hen some people come to see the patient they say, "Ah, this one! She just brought this upon herself." And they just go out and leave without showing any concern ('vasina kana shungu')....Some say that in the presence of the patient, and others say that to their relatives when they go back, and....we just hear about this in the form of rumours, (p. # 8-1).*

An urban and a rural participant expressed the same opinion regarding the stance taken by relatives and kin:

*Most of the time, with this disease that is currently around [i.e. AIDS], some think that it is a disease that people get for themselves, but others have pity and do consider it to also come when you are not suspecting, (p. # 13-3).*

*For example here, the relatives from my father's side don't help us because they say it is a disease she brought upon herself....They say it is AIDS, (p. # 5-1).*

Answering the same question on whether people have the tendency to want to know what a person is sick from first, another participant had this to say:

*I think it so happens that one would first want to know what the problem with the patient is, and how they also see the situation. When they come around asking how we have spent the day, they will be trying to assess the situation. Because when some people see you losing weight, ('vakangoona wangotanga kupera uchifamba'), they mistakenly label you, and yet you might not be having that disease. So they might ask, "What is happening here?" And they might read from you explanation that I am saying she has such and such a disease. And that sort of stops them in their tracks ['zvoita sekumudzosera kumashure'], making them decide not to get involved. But another person might listen to what you*



*say, that she is sick from whatever, and her problem right now is this, and they just help out of love, (Urban p. # 11-1).*

Sometimes support is withheld because people believe that it is a waste of resources, because the person is going to die anyway. After acknowledging the fact that people were offering support on the basis of their assessment of what someone was suffering from, one participant clearly put this point across:

*[W]hen people see a patient like that they think that it is these diseases that are common today [i.e. AIDS]. So one thinks they are wasting their money, just because people say it is incurable. That is something I have noticed...[They think] it is a waste of money....They think when one has AIDS they are already a grave, and they just look on and say, "Why bother?" ('vanenge vongotarisawo vachiti hapana chandiri kufira'),(Urban p. # 12-2).*

This type of reaction has no direct arrow representing it in *Figure 2*, because it's presence interacts with the provision of social support. It shall therefore be explained in a later section.

### Caregivers' Reactions to Stigma and Discrimination

There were many different reactions to stigma and perceived discrimination that were exhibited by caregivers, but I will try and report those that had common threads running through them. These were: not revealing their patient's illness, avoiding using the word 'AIDS', and a 'nothing to hide' attitude. But first of all, I would like to report on an important reaction observed among patients, that of not telling their caregivers what they are sick from. Because of the stigma associated with AIDS and the attendant consequences, many people suffering from AIDS did not tell even the people closest to them, that they were sick from this disease.

*Patients that do not reveal their serostatus:-* When one of my chief informants, that were also HIV+, was sent packing by her in-laws, she went back to her mother and step father's home. Although she knew the results of her AIDS test, she never told anyone.

*About my results, I never told anyone, even my mother, I never told her "Mother, this is how I am." I just kept it within my heart, because I knew my mother couldn't keep such a secret in her heart. Incidentally, it so happened that when I got sick and was diagnosed with TB at*



*...[name] Hospital... she never came to see me at the hospital. Then she started, ... "My daughter now has the disease that killed her husband..." That was my own mother telling people... (p. # HBCW5).*

From the way things went for this participant, her decision not to tell her mother about her serostatus seemed to be justified, more so considering her earlier experience with her husband when she showed him her results.

*Then I went home [tone of despair and resignation]. Yes, I had accepted it, but it hadn't sunk in yet... Then I got home, found my husband there and handed the results over to him. And he goes, "Heh, where did you get this, where did you get the virus?" and other things, and yet his hair was already frail and straight ('iye munhu aakuerera vhudzi'), (p. # HBCW5).*

One of the participants, a caregiver, also suspected she was HIV+; because she was exhibiting the same symptoms that her husband was exhibiting before he died. However, he died without telling her what he was really suffering from, and she had no knowledge of whether he knew himself or not. And, because of her suspicions, joined a support group in order to get support, mostly informational support so that she could understand the disease better.

*I didn't quite understand the disease that killed my husband. He used to have boils. He used to have boils, boils, boils, even on his genital organs he used to have herpes. He once suffered from what we call 'Njovhera' (an STD), and got treated. But...that's when he kept getting those boils and herpes, and sometimes he would lie to me...[Later I discovered that things were not okay with me because sometimes I would just feel....sick....Sometimes I get diarrhoea and I go to the toilet several times, and after that the pain goes away... And for sure we got there and we were taught how to survive [with the AIDS virus] and other things. And we were told, "This month a doctor will come and take your blood samples in order [to test it]. You know, there are certain diseases that you just know you didn't have before. [And you ask yourself], "Now...where did this come from?" (p. # 7-1).*

Two participants in the study indicated that their patients never revealed their serostatus. One was looking after three patients, but it was the one that had passed away four months before that did not reveal her status until she was on her deathbed. According to the participant, this patient had been diagnosed with TB, "but ...had been sick for a long time" before she died," (Urban p. # 10-1).

*I am not sure whether she died from TB alone or what. But...the day she died, when I took her to the hospital...she was just saying, "I am dying*



*today, I am dying today"....The doctor that last examined her is the one that...told me "Uhhh...there is no life here ('munhu hapasisina'), but [she] ...is dying from the most common disease these days ('afa nechirwere chiriko mazuva ano ichi')" [i.e. AIDS]...[later] And she even made a comment herself, at that moment, saying, "It's true doctor, that is what I have, I do not have TB". Since her husband had died, she probably knew what her husband died from, (P. # 10-10).*

The second participant still had a patient in her hands that still did not accept her serostatus, despite, according to the participant, all the evidence pointing to the fact. The "...patient used to refuse to accept that she has this disease [AIDS], saying she was being bewitched by her in-laws," (Urban p. # 12-2). The husband patient had "...died from a long illness..." and "...he had told his relatives that he [was] dying from AIDS," (p. # 12-2). But the patient would always get "...really defensive" about the matter, and "anybody that sa[id] she has AIDS was rousing her wrath, such that they would never greet each other again." According to this participant, her patient never went for an AIDS test, because:

*[S]he was arguing that she doesn't have it [AIDS]; since she was no longer sleeping with her husband at the time he died. And we told her that this virus has a long incubation period, of up to five years, during which one may not be aware that it is in their body ('tikavaraurira kuti chirwere ichi chinogara mubody mako'), more than five years, without you knowing that you have it, (p. # 12-2).*

Nothing to Hide: - A few participants were bold enough to discuss the serostatus of their patients, as well as to discuss AIDS issues in general. For example, when I asked one male participant if there ever was any time in the past month that he felt particularly stressed, he answered:

*Uhhh...[t]here are times when I end up drinking beer, for example last month when she was sick, this one with AIDS that we are talking about. She was seriously ill, and there came a time that I could not stand looking at her. Seeing her brought so much pain, you see (Urban p. # 1-7).*

Such casual references to his sister's serostatus were never in short supply in this young man's discourse. Another urban participant also freely talked about her sister's status and indicated that she never kept the nature of the disease to her neighbours.

*Myself I have never wanted to hide my sister from people. I did not like that. Some people hide sicknesses like this one. But with me, I realised that I did not have anything to hide. It is God's did, and I must put*



*everything in God's name. Because if I hide this from these people, if things should go wrong again tomorrow, they are the same people I would first seek support from as neighbours,"* (Urban p. # 11-1).

However, in the next interview, this participant expressed her concern with telling everyone about her sister's serostatus, citing concerns about some relatives that would go around spreading rumours. So, basically, there is supposed to be selective 'telling' about the true nature of the disease a patient is suffering from, according to her.

One of the caregivers that spoke openly about her serostatus and that of her husband had no qualms about talking about AIDS, even to strangers.

*I also go around making public talks about living positively with AIDS, and this has helped me to deal with the situation, and it also opens my mind. As I talk [more] about it I accept my situation and that of my husband. [As we go around] we also get to hear more information from other people as well....we have dedicated ourselves to educating others about the way we are surviving with AIDS,* (Urban p. # 7-10).

Not Revealing a patient's type of illness: - When asked what the hospital diagnosis said about their patient's illness on their last visit, most participants talked about the opportunistic diseases that their patients were currently battling with. With some, it might have been a case of knowing a patient that did not tell their caregiver the truth, or the caregiver was hiding the true nature of the disease from me. However, having been provided the information about the patient's serostatus by HBCW beforehand, I did not press the issue with any of them. During the course of the interview, however, some unwittingly began making references, for example, to how people around are saying the patient deserved what they got, or something else.

According to one participant that openly talked about her suspicions that she might be HIV+:

*We find it hard to come out in the open because you think, "Ugh, people will spread word about me." Even right now when we go for our project there [i.e. support group project], we get labelled "those with AIDS" ...So that is one of the problems we face,* (Rural p. # 7-1).

Another participant that was HIV+ and spoke on public platforms during AIDS campaigns, also expressed her reservations about revealing details about her illness to some other relatives, because:



*You don't want to tell them the details, because you wouldn't know what they will go around saying when they are away from you. Because one person might come pretending to be quite understanding or something, and yet they just want to get all that which is on your mind so that they can go around spreading that around. So it's a matter of exchanging greetings, other stories and laughing. Not talking about anything deep... (Urban p. # 7-10).*

Yet another participant that at one time spoke about not holding anything back from her neighbours, spoke of being selective about whom you tell, particularly among kin.

*You know, in a family you might be say, six or seven, but you see that one of you does not keep a secret...[but] if you tell a friend, your secrets will stay buried forever. If you tell your relative you will hear it [the secret] being told at Chikwanha there [i.e. local shopping centre]. So within a family, in fact those in my family know that [name of patient] does not want anyone spreading things that you discuss with her... If we talk about something, say we are two, as soon as you go out the door I 'forget' about it...I like a person like that... Just the same with this illness, someone comes [to see the patient], and they go out and misrepresent facts out there... You know it is very painful...[my name]; to hear someone else saying [name of patient] has AIDS. I feel hurt myself...right now the doctor explained to us family members and we know. Yes, just let it be a secret in our lives. Yes, and many people just ask, "But what is it? ('asi chiikonhayi'), looking at her on the bed. But we do have the truth that we got from the doctor inside us, but we cannot tell them. That is the secret. So, there must be two or three people in a family that can keep a secret, such that it stays forever in your hearts, (Urban p. # 11-1).*

There was therefore, general consensus that some close family members spread rumours about patients' illnesses. Even the HBCW that kept her serostatus a secret from her mother, because she "...knew [her] mother couldn't keep a secret in her heart," had her suspicions confirmed in a matter of a short time after she started spreading word that her daughter had "...the disease that killed her husband..." (p. # HBCW5).

Another HBCW confirmed some of these dynamics from her vantage point as a community person. She posited that:

*When AIDS started, people would conceal the fact that someone in their home was sick, and they would hide the patient in the house.... [But] with time, people got used to the fact that we were there to offer support, and they started coming out in the open, (p. # HBCW1).*

However, this participant was also quick to point out that even those that subsequently allow HBCW to come into their homes do not exactly tell them the patient is suffering



from AIDS. But the fact that these people knew that the HBCW and the outreach team from Mashambanzu visited AIDS patients in the community, was a sign that they had owned up. According to this HBCW, most people do not reveal their status because:

*[W]hen people know what I am suffering from, then they label me as a prostitute ('ndobva ndanzi ndiripfambi').*

Apparently, she had just given two examples of families belonging to the Apostolic Faith sect that had denied to HBCW that there were patients in their homes, resulting in the death of one before any intervention could be done. He had three wives, and one of the wives was already sick as well. Considering that a church "...stands for good things," the people had an interest in putting a lid on these illnesses because it would not present a good picture "...for people to hear an apostolic person died of AIDS!" (p. # HCW1).

When I asked this participant whether she thought there ever would come a time when people would stop ridiculing each other, or feeling ashamed of being HIV+, she ended on a positive but sad note, stating:

*[Y]oung people are reading [getting more educated], isn't it? They are becoming aware of what is happening, so really they know, that one can contract this disease, if we don't do what? Restrain ourselves. Us, the older generations are the ones who look for a reason, an explanation for how it has happened [i.e. infection]. Therefore, we used to blame it on witchcraft. So, there will come a time when people will begin to accept. The very young ones will accept, only if us the mothers do not speak on their behalf, telling people that 'my child was bewitched'. Otherwise they will tell people the same thing, thinking 'because my mother is saying I was bewitched, so I will hide behind that.' But there will come a time when everyone will accept, because there is not a single house that will remain unaffected, (p. # HBCW1).*

*Avoiding the use of the word AIDS:* - Most of the participants never mentioned the word AIDS in all the interviews I did with them. Even those that were open to talk about AIDS would most of the time use other words or referents. The participants were simply pulling a page from the stance the government has traditionally taken regarding this issue. Through much of the 1980s, into the 1990s, HIV/AIDS was barely acknowledged. Whenever someone prominent died of AIDS, the media, and in turn the community, would refer to them having been "sick for a long time". Hence not many deaths were attributed to AIDS. For example, one urban participant that was looking after a sister said that, "The husband [i.e. sick sister's husband] had the knowledge that he had AIDS, and



he told his relatives that he [was] dying," (p. # 12-2). Yet, the first part of her response to my question asking what had killed the husband was, "The husband *died from a long illness...*"

The new jargon that people have come up with to connote one is sick from AIDS is that someone '*anorwara*' or '*arikurwara*', literally meaning '*he/she is sick*'. Since it is no different from the normal referent to someone being sick from flu or a cold, one has to discern the tone in which the words are said, either said in a whisper, or prefixed by '*Uhh*' or '*Ahh*'. Close observation also reveals that when some mention these words they avoid eye contact. Another jargon is '*anechirwere*', meaning '*he/she has the disease*'. For example, one participant said:

*If you ask somebody to come and do it [i.e. bath the patient], they will refuse, fearing contraction the disease ('chirwere'), you see (p. # 3-4). [own emphasis]*

Another good example is that of a participant who was looking after a son, but was talking about how her sister-in-law couldn't support her because:

*She also has two daughters that are sick. They live just across the river....Ahh, they also have this disease ('vanacho ichochi chirwerewo')...(p. # 4-1). [Own emphasis]*

What makes this case more interesting is that this participant had never indicated that her son was sick from AIDS. Another participant that felt her brother had refused to let her sleep at his home during her visit to Harare for a medical appointment said, "...maybe he thought I have this disease..." (p. # 7-1).

Those that are slightly more specific, however, would say, '*he/she has this modern disease*' ('anechirwere chemazuva ano ichi'). Here are two variants of this usage:

*When people see a patient like that, they think that it is these diseases that are common today....Right now she is seriously ill; I think it is this disease that is around these days, (p. # 12-2).*

*Most times with this disease that is currently around, some people think that it is a disease that people get for themselves...(p. # 13-3).*

Other participants used wishy-washy referents, as depicted in the following examples:

*These days it is difficult [i.e. to get support], because some will be afraid the patient might be suffering from this disease or that disease, (Urban p. # 13-3).*

*That she is sick. She is this, she is that? (Rural p. # 3-1)*

*[S]he has a younger sister of hers that died under mysterious circumstances last year....Plus she has another sick younger sister that*



*also has a sick child right now, again, both sick from things that people don't quite understand, (Urban p. # 2-3).*

The overall message one gets from all this is that AIDS is an unmentionable. Even some people in the medical profession resort to using such language, as revealed in this example:

*But I think, the day she died, when I took her to the hospital... The doctor that last examined her...told me that 'Uhh...there is no life here ('munhu hapasisina'), but [she]....has died from the most common disease these days – AIDS ('afa nechirwere chiriko mazuva ano ichi', (p. # 10-1).*

There are two possible explanations for these reactions. Either people do it consciously in order to avoid talking about a taboo, or it is an unconscious reaction to the wave of stigmatisation surrounding AIDS. AIDS is associated with sexual intercourse as well as prostitution, a combination of subjects the *Shona* custom does not 'permit' to be discussed in public.

#### What it feels like to be stigmatised

This section deals with caregivers' experiences of stigma, what the experience of stigma made them feel. The focus of the section, therefore, is just on the caregiver, the right hand portion of the Venn diagram in *Figure 2*. Most participants felt that people that thought they could catch AIDS from casual contact with an infected person had little knowledge about what is involved. According to one participant, "There are very few people that understand," (p. # 10-1). Those that spread rumours were regarded as exceedingly insensitive.

Some participants were neutral in how they said they felt towards stigmatisation. Even though it hurt, they presented a picture of having gotten used to the shunning and ostracism.

*Before I learnt the importance of 'coming out', for sure I used to get very angry. What made me angry is that 'we' hadn't learnt that there are many ways of getting this disease. 'We' used to think that it comes through heterosexual intercourse only....We don't understand that the disease comes through different means, such as using [contaminated] razors and needles....That is why I used to have these many thoughts, eating my heart out and wanting to kill myself, because of the way I used to be laughed at and being loathed...(Rural p. # HBCW4).*



Another participant whose neighbours – after their husbands greeted the participant as they passed by her house - would shout insults, saying that if they ever got AIDS they would know who they got it from, said: "You just go, 'Aaa, it doesn't matter.' You don't try to answer that person, you just keep quiet until the situation calms down," (p. # 7-1). Responding to how she is shunned by neighbours who no longer accepted to eat any food in her house, and never came to borrow little things, such as salt, she said:

*And you just say, "God, you are the one that decided to give me this."  
There is nothing you can do; you just have to accept it, (Rural p. # 7-1).  
[My emphasis]*

Although it might seem this participant was taking things in her stride, her fear is revealed in this sentence:

*And we find it hard to come out in the open because you think, "Ah, people will spread word about me."*

Her vulnerability was again exposed by her reaction to her brother's refusal for her to stay overnight in his house in Harare. She said that "...really disappointed..." her, and she started to have many thoughts in her mind, imagining how he must have been afraid that her using his towels would make him contract 'the disease'. Another participant that talked about relatives and friends "...now refus[ing] to have anything to do with [them]," and said "...things that ma[de them] even worse...", said that they had become "used to it now," (Urban p. # 7-10). But having to be given her own cup and plate to use, and being evicted from a family home by a brother made life "unbearable" for her. In resignation, she just tells herself that, "...there is nothing you can do about it."

Both participants 7-12 and 7-10 indicated that there was nothing they could do about the situation, which gives a sense of *powerlessness*. These are social dynamics beyond their control.

Another participant that exhibited a sense of powerlessness against the waves of gossip about her brother said, "It doesn't matter, even if it is AIDS, because we will all die anyway, from whatever cause," (Urban p. # 3-4). In her sense, others might seem powerful by not contracting AIDS, but in the end, death becomes the greatest leveller; we all become *powerless* in its presence. Also powerless to stem the tide of gossip about her daughter's and grandson's illnesses, as well as (successful) efforts to stop prospective tenants to rent her rooms, one participant said the experience was "*painful*", (p. # 4-5).



Another participant that expressed a sense of being disturbed about rumours about her sister said:

*You know, it is very painful..., to hear someone else saying ...[name] has AIDS. I feel hurt myself...It is ideal [for it to] be just...a secret in our lives," (Urban p. # 11-1). [my emphasis]*

Another participant also expressed feelings of hurt regarding relatives that do not visit to check out on his baby's illness.

*[S]uch things have always troubled my mind. What comforts me is thinking that maybe that person also has their own problems...But in my heart I will be quite troubled by the reason why my relative isn't coming to see me and how things are. But I put myself in check when I realise that they also might be having problems....I [also] sometimes think that maybe I am becoming a pest to them....I am putting a burden on someone who also has their own family....because there is no way of knowing what is inside a person's heart [i.e. mind]. I sometimes think that, (Urban p. # 9-8). [My emphasis]*

Feeling troubled as this participant did is what another participant experienced, a HBCW that got rejected by three different sets of close families because of her serostatus.

*I was reduced to destitution....[and] this was an issue that kept bothering my mind, (p. # HBCW5).*

Causing more pain was the fact that her own mother generated the wave of gossip about her being sick with "...the disease that killed her husband...". It was as if she didn't believe a mother could ever do that to her offspring.

*That was my mother, telling people, right? The one person that gave birth to me!*

The general feelings in response to perceived stigmatisation and discrimination are therefore, those of: pain, hurt, feeling troubled, and powerlessness.

## **Giving and Receiving Social Support**

### The Social Rules of Giving and Receiving

Rules of giving and receiving are governed by cultural norms and expectations. In this study, these rules were affected by practical circumstances (i.e., the current economic



hardships and state of deprivation affecting the social networks participants belong to). The effective application or observation of these rules was also compromised by people's reactions towards AIDS, PWHA, and their caregivers. In this section I will discuss the general rules of giving and receiving from the perspective and experiences of participants in the study. Some of these perspectives and experiences are more general and do not necessarily have to do with support related to caregiving or AIDS. The section pertains to the cultural norms existing in the large circle in Figure 2, labelled 'Community', of which the PWHA and their caregivers are a part. It speaks to the norms guiding support receipt and giving among kin (i.e. the smaller innermost circle), and among neighbours and friends (i.e. the middle circle).

As I mentioned in previous chapters, the participants in this study come from a society where collective consciousness has traditionally dominated social, productive, and consumption activities. A major sub-theme that came out of this study concerns the rules governing support giving during funerals. This is one social activity that, up to the present times, still draws from the traditional norms of support giving. What makes it easy for people to support each other or reciprocate such support is the inevitability of death, for oneself and one's relatives, and that one will need that kind of support in future. This is a social activity that demands a lot of resources and emotional support, lasting two to three days. Every participant at the funeral has to be fed.

Therefore, when there is a funeral, neighbours, friends and kin "...come together and help each other....giving each other ideas, and if necessary to make monetary contributions ...and share expenses..." (Urban p. # 13-3). According to this participant, apart from sharing ideas, it is also important "...just [to] sit around and comfort each other (munongosvikogarawo muchiitasei? muchingokumburana...makagara'), or "...help with cooking...or other chores where necessary." These are the only times that this participant said they helped each other with her neighbours, "...when someone has a tragedy." Most urban participants also indicated that whenever they had a funeral and they were going to bury their relative in their rural home, friends went along with them to offer support, and they also helped their friends in a similar manner.

*One might have experienced illness or death in the family. If it's a death in the family, you might accompany them...[to their rural home]. This is*



*because you don't want our friend to think too much about the death,*  
(Rural p. # 2-1F).

According to one urban participant, family members and kin always come together to plan things when there is a funeral.

*In our family when there is a problem we sit down together and discuss how each one can contribute. We have always contributed, at funerals, or when there is an illness... We have always had that unity,* (Urban p. 2-3B).

Even for families that might not be as organised as this one, support does not have to be asked for at a time like this.

*Once they [i.e. relatives] know that so and so has a death in the family, they come together on their own in that rural home to put together resources to help the one whose child has died,* (Urban p. # 5-6).

This was also an indirect reference to what had happened a few weeks before when one of her patients, a daughter died and they took the body to their rural home for burial.

When family members are hard up, and other community members cannot contribute enough to meet costs, it is close kin to borrow, as maternal relatives did at the funeral of one of two of this participant's patients: “[A]t the funeral they ran around to borrow money, so they could bury this boy [i.e. brother]...” (p. # 3-4).

With funerals, concerned relatives, but mostly friends and neighbours do contribute according to the resources they have. There are no set standards or limits.

*If it is contributions at a funeral ('chema'), you just give whatever you can afford. The important thing is to contribute to the job at hand,* (Urban p. # 13-3).

In most communities, neighbours organise themselves to go around collecting the basics, such as corn meal and cash, from the village (in rural areas) or surrounding streets (in towns). This organisation is done without the request of the bereaved family.

*For example, when there is a funeral...they go around collecting corn meal and money, which is like a burial society...* (Urban p. # 15-5).

*Moreover, on this street, we made an agreement that whenever each one has a funeral at their home, each one contributes a certain sum of money, and corn meal.... to allow whoever has been affected to help themselves. To come up with those things we would have sat down, the women that live on this street, then looked at the things that are needed most at a gathering. Then we see that food is the item that is more problematic,* (Urban p. # 11-1).



For those that cannot afford to contribute anything in terms of money, there are always opportunities to cook for attendees or washing dishes. There are also opportunities to participate in the all-night singing and dancing ceremonies.

Close friends are also expected to sleep over for a day or two at the home of the bereaved.

*When I hear there is a funeral [somewhere] I rush there. Sometimes I spend the whole night there, then come back [home] after the burial, (Urban p. # 15-5).*

There are also similar norms related to sleeping over at a patient's home that are binding, particularly for close relatives. On some occasions, this can involve even living in the patient's home until the condition improves. All the while, the visiting kin will be offering support to the patient and primary caregiver.

*I am the one notorious for going into people's homes. Even if they [i.e. friends] happen to get seriously ill, I am the one to sleep over at their home, looking after them, (Urban p. # 4-5).*

*In fact I would say, this past October, [patient's name] was admitted into hospital on the 12<sup>th</sup>, and came out on the 17<sup>th</sup>. After she came out, her illness never changed for the better. It remained critical, and during those difficult times there were a lot of relatives living here. And each one just shows me how they see things, and what they think about the situation. They really supported me, (Urban p. # 11-1).*

Whenever relatives come over to stay for a while or to sleep over, they do not normally come empty handed, as is the case with this rural participant that was looking after a son.

*Most of my relatives are female....Now, these girls have their own homes, so they only come to spend the night, "We have...come to spend the night with you, so that we can see to the patient together." Then they do whatever they want with their 'son' [i.e. nephew], to show their love. They buy him food, and they console him very nicely, (p. # 4-1).*

Visitors that come to see a patient are normally 'expected' to bring something for the patient. Visitors also feel obligated to bring something for the patient. In this study, participants mentioned such items as: fruits, soft drinks, and money to buy some food items that the patient(s) preferred. One participant that talked about the support she got from friends said:

*One might come with some eggs and say, "Here...cook them for the patient." And another might have some tomatoes, and says, "Go and use these to cook for the patient." Yes, that way she has showed her love,*



*because you haven't asked for her help, it is her desire to do so, (Rural p. # 4-1).*

Relatives that live close by, and neighbours, are also bound by norms that govern the provision of moral or emotional support to caregivers. I will confine myself to the subject of greetings during different times of the day, particularly in the morning. It is customary to pass by the caregiver's home and ask how the patient has spent the night or day, regardless of the status of the illness.

*Whenever they (i.e. neighbours) see...even when there is no serious illness. In the morning they come to ask, "How has mother spent the night? How has sister spent the night?....Whatever the time, even in the afternoon they do enquire [about the patients' health] ... (Urban p. # 14-4).*

Another rural participant that believed her relatives cared about her, "...because everyday, without fail, [she] meet[s] someone that supports [...her] in connection with [caregiving] problems..." said:

*There has to be someone that comes by to ask, "How have you spent the night? How have our patient spent the night?" (p. # 4-1).*

Even neighbours are supportive because, "Whenever they come to see the patient, be it sunset, in the evening, or morning, they ask, 'Has he eaten? How is he? How has he woken up? What have you fed him with?'"(Rural p. # 4-1). When there is an illness in one's neighbour's home, therefore, one is obliged to go and ask, "My friend, how has the child slept?" (Rural p. # 7-1). According to another participant, "...there is one person or the other coming here all the time to ask, 'How is your mother? What seems to be the problem here?'" (Rural p. # 5-1).

Another theme running through participants' discourses was the fact that relatives and neighbours do not have to be asked for support. The least one could do is bring to their attention what you are going through, but not ask for support.

*They [i.e. relatives] just reason on their own that it has been a long time since they last came to see me. "She is facing problems with her son," so you see them coming to spend the night, (Rural p. # 4-1).*

Close neighbours and relatives, customarily support each other with small things, and one such item commonly mentioned by participants was salt. Because of the seriousness of this process of exchange or borrowing of salt, one participant said that they



had named the small gate on the fence between their semi-detached house and their neighbours' the 'salt gate' ('kagedhi kesauti').

*Most times they come, "Can we please have this, can we have that?" Isn't it I told you we call that the 'salt gate'? They come to ask for salt, soda, and other things such as cooking oil, (Urban, p. # 2-3).*

Neighbours and friends, however, do help each other with things bigger than salt, as shown in the next two examples. The first example is that of a neighbour that lived in the rural areas, but came to her urban home once every month. On her visits, she always brought her friend things that she thought she could use is her family that was undergoing difficult times because of the illness. The second example is of two rural friends, one being a caregiver that helps out a friend that is also HIV+.

*She came from ...[name of rural area] yesterday.... She brought me some wheat. She said, "Have this ground into floor so that you can make bread for the children. That is what I could afford to bring with me." So, you realise that such a person thinks about you everywhere she goes...Last month she brought me some onions, vegetables, which I put in the fridge (Urban p. # 11-1).*

*[I]f she says she doesn't have money for the grinding mill, I can take some and give to her; even if she says she doesn't have sugar, I realise that it would be improper for me to drink tea when she doesn't, so I give her. [N]ot too long ago she said she didn't have any cattle to plough her fields with. She was starting to dig her field by hand, and I said, "With your illness, it's not good for you to be digging the ground. Right now the cattle that I have seem to be having too much work, so what I can do is, instead of you digging by hand, it would be better for my boys to do some ridges for you [instead of ploughing], so all you will need to do is weed." So I have managed to make ridges for her (Rural p. # 1-1).*

These have been some of the unwritten, subtle, but important social rules affecting giving and receiving. There are, however, other customary rules that are even more binding. There is a somewhat strict protocol that is supposed to be used to communicate with maternal relatives, regarding the illness or death of their daughter, or son. With a woman or daughter-in-law, this concerns notifying her parents; and with regard to a man (e.g. someone's father), this involves notifying his mother's clan (i.e. his mother or her brothers). In the event of a life-threatening illness or death, there has to be sent someone to go and personally deliver the message. If this is not done, they will boycott attending the funeral, and they will have to be compensated by a cow or a goat, whichever they choose as fitting the 'crime'. That boycott means there will be no one to



perform the rites that they should traditionally perform, and the other supports they would ordinarily give under such circumstances are not provided. One participant showed deep concern that her sister had been sick for a year, and was then bedridden, yet they had not notified their dead mother's brothers that their niece was sick.

*There is no money for us to send someone. You know, on the mother's side there needs to be sent someone to go in person, not to write a letter, according to our [Shona] custom, (Urban, p. # 12-2).*

Another customary rule governing giving and receiving is called '*chiredzwa*', whereby a relative that looks after someone's child for a relatively long period of time is compensated for their support. In this study, one patient, whose son had been looked after by an elder sister did not show any appreciation, incited the wrath of the elder sister, who was now withdrawing her support on that basis.

*[S]omewhere in the middle there, there were some family matters. And people sometimes want to revenge at a time when one is in trouble.... Because our eldest sister and her husband are the ones that raised this older boy of hers. And after all that, this sister here never gave anything as a thank you for raising this child. When the child came back she never even asked how the child came, she just took the child in and kept quiet, and she stopped going to our sister's house. You see. And when that older sister was told that her sister was sick, she just said, "Does she know me? Has she been coming here?" So they have been ignoring each other, and she is revenging at a time when the other one is ill, saying, "She has never cared about me, so what does she want from me?" That is the problem here... (Urban p. # 12-2).*

The last traditional norm that I will look at is the one that is prevalent among most low-income households. Due to a lack of social security, most parents' social security rests in their children, whom they expect to look after them in old age. According to one participant, one reason why her relatives are not supportive of her sick other is that they expect her children to do the supporting.

*You know what we do in our African custom? Each one takes pride in their children, with the hope that they will support you tomorrow. So I think this is what they think, "She [i.e. mother] has her own children, so they will see to things by themselves, (Urban p. # 14-4).*

Another participant expressed the same sentiment, saying:

*They...know that this one has nothing for sure, our relative has nothing, so let us help her. But others go, "Aaa, don't concern yourself with her, she has her own children. She will get support from her own children, (Urban p. # 5-6).*



The Social Rules of Reciprocity:- Rules of reciprocity also determine the flow of support between friends, family members and neighbours. Even the attendance at funerals that I have discussed above is somewhat based on the principles reciprocity.

*Ah, no, no he [i.e. friend] cannot just continue to help me without my doing something for him, you see. We help each other. When he has a problem, or there is a funeral... For instance, there was a friend of mine that used to live here, when his mother died we went all the way to Mozambique for the funeral. I accompanied him. And if there happens to be a funeral in this one's [i.e. current friend] family I can also accompany him to his rural home in Domboshawa... (Urban p. # 1-7).*

Another participant narrated how she and her two close friends reciprocated support in general, as well as support related to funerals. Of particular importance is how she got assistance on her brother's funeral, and how she also assisted her friends after that.

*I would say in our friendship, the three of us, when each of us is confronted by a problem, we have to see that we stand up to face it, the three of us. Both these people know my rural home, and I also know theirs, and this has been necessitated by problems we have faced. A brother of mine that came after me died 1997 September. These are the people I went home with [for the funeral]. When we left this place going to Mbare [bus terminal] ... they did something that made me realise these people love me dearly... [O]n our way from Doves Morgans [i.e. undertakers] ... [we discovered] they had already bought sacks of cabbages, and dozens of bread. My brother asked if I had given them money [to buy those things], and I told him I hadn't, these were people that were sharing our sorrow. So, this other friend of mine, the one that lives here in ...[name of suburb] later lost her older sister, and we went to [her rural home] together... I just bought what I could, and they saw that I cared. And this other one also lost her older sister this year in January. And we went to her rural home together, (Urban p. # 11-1).*

A good number of participants believed that one good turn deserved another, or simply, one gives to those that give them in return. In *Shona*, there is a proverb that says, 'Kandiro kanoenda kunobva kamwe', which means one good turn deserves another. A related proverb goes, 'Ukama igasva, hunozadziswa nekudya'. Literally this means relations are not full, they are made full by sharing food. However, the actual meaning is that kinship ties are strengthened by supportive deeds. The following dialogue, in which a participant used the first proverb, serves to make the issue of reciprocity in *Shona* custom clear:

I: Are there any relatives that you help yourself?



*P: Yes I help them.*

I: With what?

*P: I help them with whatever I will be having at that time.*

I: Things like what?

*P: If they come and ask me for vegetables, onions or...I just give them.*

I: What do you feel after giving someone something?

*P: I just feel good free, because they say, 'Kandiro kanoenda kunobva kamwe', a proverb says that.*

I: By this you mean they also help you?

*P: Yes, and then I also give them what I have.*

Another participant that I had asked if she thought people help others so that they get help in return said, "Yes...that is what we do. We think, 'Ah! ...if I refuse to help them, one day they will also refuse to help me.' That is what we do," (Rural p. # 7-1). When I subsequently asked her if she agreed with the proverb used by the participant quoted above she said, "Yes, that's it exactly. He/she will be thinking, 'If I help her, what will she help me with? She has nothing she can help me with.'" Instead of answering for herself, she answered on behalf of people she interacts with. In other words, this participant thought other people first of all looked to see what she had to offer in return. But nevertheless, she agreed to the concept conveyed by the proverb.

A number of participants seemed to think that nowadays people are finding it easy, or rather choose to help those with the means to reciprocate, or "So that we get help in return, because she has got resources..." (Urban p. # 5-6). In other words, people "...look forward to being helped in turn," (Rural p. # 5-1). A participant that put this notion across more aptly and interestingly said:

*Aaaa [reflecting], that is now common these days. It's like right now; I am in the middle of this crisis, but I do not see any relative. But if they happen to hear that I am now an announcer at the Broadcasting Corporation there, hearing my name and seeing me in the news, you start seeing relatives coming. Just because I am popular, but during the times when you are in trouble, let's not lie to each other, you never see any relative....[later] Myself, since I live in remote [rural] areas, you see very few people visiting you in rural areas...none of your real relatives ever come. But if I had a good life, and they knew that their sister had lots of cattle, and many fields, I would see them. But for now, since I do not have all these, I do not see anyone, (Urban p. # 12-2).*



For another participant that took the perspective embodied in the proverb about reciprocity religiously, the inability for one to reciprocate would mean the end of a relationship, not just withdrawal of support.

I: If you were the only one supportive of your friends, and they didn't help you at all, what would you think?

*P: I would say that is the end of the friendship, I will just break it.*

I: When you support someone and they do not support you in return, not even giving you words of comfort, what do you do?

*P: You give them another chance, and if you realise that they have nothing to help you with, you just leave them alone.*

All these participants were talking about *mutual reciprocity*,<sup>12</sup> however, there are some participants' views that brought a twist into the whole concept of reciprocity, when they suggested that helping someone is not based on one's expectation of having that act reciprocated by them directly. According to the following participant that talked about *univocal/ directional reciprocity*, the proverb 'Kandiro kanoenda kunobva kamwe' is supposed to have a broader interpretation, such that one does not expect to get support reciprocated by the same person, or immediately thereafter ("it will come back some other day"). This is how the dialogue went after asking the participant what she thought about the proverb:

*P: [laughs] It is quite true, that 'Kandiro kanoenda kunobva kamwe'. If you help someone, you shall also be helped, receiving even more than what you helped with.*

I: Say you have helped someone, and when your mother gets sick and no one helps you, including the one that you helped before. If they should encounter any other problem, would you help them?

*P: I can help them if I have the means, I don't care.*

I: But they wouldn't have reciprocated the initial support...

*P: It doesn't matter [laughs], it will come back some other day. It might not be them that return it. It might be returned by somebody else.*

I: Another relative or somebody else?

*P: Yes.*

I: But it's not them that have returned it?

*P: No, it doesn't matter [laughs].*



Two personal life experiences of one participant fittingly portray the concept of *invocal/ directional reciprocity*. The participant got married to a man whose father, a businessman, who had six wives. However, when she got married, the husband's mother had already been divorced. After getting married, the participant's husband went to his maternal relatives to get his mother, who came to live in her daughter-in-law's house, but died in 1994. The husband's stepmother, one of his father's wives that looked after him after his mother had been divorced, also visited sometimes. The husband told her that this stepmother who fed him in his mother's absence saved his life. When I asked this participant if there are any relatives that she also supported she answered:

*So that got into me as well, and I realised that she helped a lot and I should help her as well. I would pay school fees for her children, or buy clothes for [some of] her children at Christmas when we were going to our rural home...then buy for the others when we went back for Easter. And those children have never forgotten me, even up to now they do come here. Their mother died February this year, but before she died she would come and ask me to buy her clothes and canvas shoes...Her child once fell sick, and I brought him here with me. He got admitted into Harare Hospital with a heart problem, and we stayed with the mother for three weeks, until he was discharged. By the time he left here I had done a lot for him, things for him to take home. My husband and I are the ones who looked after him until he died. The funeral was done here and we went to ...[rural home] for the burial. And we went to pick up my mother-in-law from ...[rural home] when she got seriously ill, and she died at Parirenyatwa Central Hospital. The funeral was done here. So...I think that my husband has realised that I care for other people, and that's why he does nice things for me. This is not the first patient we have looked after in this house. I have looked after his relatives well, until they died and we buried them in good spirit. So I think he has that desire to be supportive of me because I have been nice to his relatives. I think if I had been cruel to his relatives he might have just said that he wasn't prepared to look after my sister [in our house]...So what I think is that he must have seen that I looked after his relatives well and he must also look after mine, (Urban p. # 11-1).*

In this example, the participant believed the husband, in agreeing to take her sister in; he was reciprocating the support she had always given to his relatives. My other example is also based on the life experiences of this participant. The example was a one-time gesture of benignity to a neighbour.

*For example, the woman from there died, and [one day] I saw the child coming here crying. I called her and asked why she was crying. She said that she had been chased away from school because she had not paid her*



*school levy, and the father was in the rural area, and her sister was [away], at school...I...had a fair amount of money on me, [so] I called that child and gave her money, \$70, and told her to go back to school and pay her fees. And she said she would tell her father to pay me back after they got paid by their lodgers [tenants]. I told her not to worry, because where I go to sell my jerseys and clothes in...I do not pay for food or bedding. I just get help from people who sympathise with me. So I must also help other people...So you can't just expect to receive help from others without being able to help others...[W]hen the father eventually came back he came here... and I told him [what had happened] ... So he gave me \$100 and I refused it. Then he thanked me and left, (p. # 11-1).*

Some participants did not agree with the concept embodied in the proverb 'Kandiro kanoenda kunobva kamwe' outright. For example, one participant that I asked if she thought people helped those they knew would be able to reciprocate said, "[although] some people think like that for sure...just love is what is required...love in whatever you are doing," (Rural p. 6-1). Asked the same question, another participant flatly refused to accept that that is the way people should coexist.

*[D]uring these present times there is no longer any discrimination. Even a person that is not my relative, if I get anything to help them with, I just help them. Everyone on earth is my relative, because we were chosen to coexist on earth by God....If I cant find something, that's okay, I can console them....What I do is, God has given me so that I can extend my hand, because it doesn't matter they once refused to help me. Maybe it was because they didn't have anything. [God says] "It matters not, just extend your hand to them. I am the ones that records what you give out,"* (Rural p. # 4-1).

Other participants refused to accept the concept embodied in the proverb, but their actions seemed to support its principle. For example, a participant that was on the verge of a divorce with her sick husband talked of how everyone in the family would try to stop her from associating with a sister-in-law, but she remained resolute in her support, because the former seemed to be on her side.

*I also used to go and see her. And she would send her child to come and ask for corn meal from me and I would sneak it out to her. Because if anybody saw me doing that they would shout at me, "Why did you give her?"...She lives with her children only. And, when it comes to these issues [divorce issue], she is the one that often stands against the rest of them, saying to them, "You do this to ... 's [patient's name] wife, don't you see all the good things she does?" Because I also do good things for her. I used to go and see her, (Urban p. # 6-12).*



Some participants generally agreed that most people helped someone with the hope of being helped in return, but distanced themselves from such a belief. For example, when I asked one female participant how she would react if she helped someone that subsequently failed to help her, she replied, "No, it is not proper that when I help someone I should look forward to getting help from them; maybe they won't be having the resources," (Rural p. # 5-1). And another participant that had earlier indicated that they did not believe in 'the proverb' said:

*When I help someone, I help them with the expectation and thought that I am helping my relative, tomorrow I will be faced with a similar problem, and they will also help me...and you will be helping from deep down your heart... (Rural p. # 2-1F).*

Proverb or no proverb, participants' stories were full of examples of instances whereby friends, neighbours, as well as relatives reciprocated support. A number of participants that owned houses in which they rented out rooms reported instances whereby their tenants supported them with food items for the patient(s), some change to buy food items for the patient, as well as emotional support. Although tenants pay rent to their landlords, the fact that they could be told to pack and go with or without notice any time, is a sure reason for one to want to be on the landlord's side, because being allowed to stay on is regarded as a 'favour'.

Participants also had a lot of discourses portraying how they reciprocated support with close neighbours. For example, a participant that had indicated that her neighbour always came over on different times of the day to check out how her three patients were doing responded to the adequacy of the support she was getting from the neighbour by saying that, "...since this is a person who also comes to ask for support, therefore, you just see that things are at par," (Urban p. # 10-1). Another participant that talked about a neighbour, who was also a friend, that used to come and give her emotional support, which she said "...actually made my burden lighter," also talked about her friend coming for support from her.

*For example yesterday, I think she had problems with her husband, and she came crying, wanting to go to her parents' home...So, whenever she has a problem at her house she also comes over, or shouts across the yard, and then we laugh as we talk about it [laughs all the way as she talks], (Urban p. # 14-4).*



This was a neighbour that lived close to the participant's home. However, the same participant also talked about neighbours that lived next to her parents' home, where her patients lived. About these neighbours she said, "We support each other." These are neighbours that would come everyday, checking on her patients. During that time it was her that had patients, but not too long ago the neighbours had a patient as well.

*For example, they have a child that passed away recently whom I used to buy bananas for...So you can see that we are families that get along very well, (Urban p. # 14-4).*

Another urban participant also talked about her neighbouring friend, who also had a sick brother that had just passed away. These two would visit each other's patient(s), hence she commented, "I would go to see him yes, and she would come and see my patients," (p. # 3-4). For another female participant that also had two patients, a neighbouring friend is the one she "...burden[ed] with [her] frustration." But in the same process, "That's when she [the friend] also tells [her] about her problems..." (Urban p. # 4-5). A male urban participant that owned a home also talked about most of his neighbours, whom he said he "...g[o]t along [with] very well," (p. # 15-5). However, there was a particular neighbour whose water pipe was giving them problems at that time, and he commented: "Certainly, we support each other. Even when we have a similar problem we go and get water from their tap, or little things such as salt..." Borrowing from neighbours and reciprocating their support seemed, therefore, to be a common practice among participants, regardless of the presence of an illness or not.

*Yes, we borrow from each other. They also come to ask for salt or corn meal, and give us when they buy theirs. Yes, it's a matter of borrowing from each other... (Urban p. # 6-12).*

Norms or reciprocity do not only apply to neighbours or friends. They also apply to relatives, but most importantly, they were seen to apply to interaction processes between patient and caregiver. A number of participants talked stories about how they felt indebted to their patients, because they had offered them support at some point in time in their life. One urban participant had just come from her rural home to look after a sister, leaving behind her school-going children under the care of a grandmother, whose health was also failing. That being a cropping season, she also had to forgo the vital activities of land preparation and sowing. According to her, the sick sister was "...the one person that [had] been giving [her] advice and support, " (p. # 12-2).



*She is the one person that has been close to me to whom I could take my problems, and she would respond favourably, you see (Urban p. # 12-2).*

Another poignant example is that of a participant that had raised her younger sister in her home, until she got married. When the participant fell sick, the younger sister brought her into her home, 450 kilometres from Harare, so she could look after her. Now the sister also felt obliged to look after her younger sister.

*For example myself, I once got sick in 1995. Her husband drove here [from Bulawayo] and took me with him so that I could have a change of environment. My husband agreed, and I went together with my mother, and lived in ...'s [patient's name] house for three months. They looked after me quite well. And her husband was also a very kind person. Therefore, we used to understand each other pretty well. So, she also looked after me, and God also knew that in the end I would look after...[patient's name], (Urban p. # 11-1).*

Despite most participants' wish to reciprocate support, or to have support reciprocated, things did not always go that way. There were participants that indicated that they were not able to reciprocate support given to them, mostly because they did not have the resources. On the other hand, some said that they reciprocated by offering moral or emotional support, if they could not afford to give instrumental support. For others, such as one young man who used to get instrumental support from his well-to-do aunt, reciprocity meant what he could afford.

*There is nothing I can help her with, because I do not have anything. The only thing I can help her with is by running errands for her, (Urban p. # 1-7).*

Inability to pay back or reciprocate was cited by some as the reason why they did not approach relatives, friends or neighbours to ask for support. One male participant that aptly captured the fear involved by saying:

*I can't do that, because if I go to them and ask for support, I become indebted to them, (Urban p. # 15-5).*

When I asked him what he would do if he did not have to pay back he said, "Ah! No [short laughter], I am too shy...because I do not want to make enemies with people," (p. # 15-5).

While this participant was worried about his inability to return a favour, some were worried about not getting favours returned.



*I am one person that is very supportive of my relatives and friends; but what do you see in the end? They do not return whatever you will have done for them yourself, (Urban p. # 2-3).*

Speaking particularly about her younger sister that was not supportive, she said:

*[M]aybe that is just the way she is, but if they have any problem they call me, and I end up running around...I do not let them face it alone, I help them a lot. They [with husband] are just hard-hearted...[later] I just accept her as she is; but knowing that she is hard-hearted herself, (p. # 2-3).*

A grandmother that was looking after a daughter and a grandson also expressed her displeasure about the failure of the few friends she had to reciprocate the support she gave them.

*I realise that they are desperate...Then I give them something, "Make porridge for the children." Or, if I happen to have vegetables in my garden, I take some and give them, even a bit of salt. But what do they go ahead and do? They do not reciprocate. Not a single bit, if you have an illness in the family like this, they don't even notice you are there. Uhuh, they instead laugh at you, saying, "They are sick, so where are they going to find food to eat?"...[later] [Yet] I used to give them food, thinking I was helping God's souls, and yet I was wrong, (Urban p. # 4-5).*

While this participant seemed riled enough to discontinue supporting her neighbours, some never took a neighbours failure to reciprocate support to heart. A good example is that of a female participant that had two patients. When a next-door neighbour's husband stroke, and was hospitalised, she would visit him in hospital, but when her children fell ill, her neighbour never came to visit. Because she never took that to heart, she said that she still continued to support her neighbour.

*I plant early, and like right now, I already have pumpkin vegetables in my field there. I reap and give them some for free. The maize that I grow in the vlei there also ripens earlier than other people's. I also gather some and give them, because they are our neighbours, (Urban p. # 5-6).*

Social obligations to help kin: - All participants were full of stories concerning how they help their kin, and how their kin or some of them assist them in connection with the illness as well as in general terms. While some might have felt that "...someone who is not your relative never considers your situation" (Urban p. # 6-12), some thought differently.



*[D]uring these present times there is no longer any discrimination. Even a person that is not my relative, if I have something to help them with, I just help them. Everyone on earth is my relative, because we were chosen to coexist on earth by God...If I do not have anything...I can console them... (Rural p. # 4-1).*

When it comes to caregiving, participants felt that they had an obligation to help their patient(s), because they were close kin. Hence, despite the complexity of the problems related to caregiving, comments such as the following were quite common:

*Seeing her brought so much pain. Blood is thicker than water; whatever comes, your mother's child is your mother's child, (Urban p. # 1-7).*

*You just tell yourself, 'What can I do when this is my father's child?' (Urban p. # 10-1).*

*[T]o be seen refusing to look after your mother's child because you are afraid is not proper, (Urban p. # 11-1).*

*Sometimes you feel repulsed by it all, but it's hard [not to help] if the person fighting for life...is your relative, (Urban p. # 12-2).*

*It comes to a point when it becomes hard to cope, but since you were given birth to, there is nothing you can do, (Urban p. # 14-4).*

*In fact, when it is your child there is nothing you can say is problematic, no matter how heavy the load becomes... (Urban p. # 5-6).*

*There is nothing I can do, because she is my child... (Rural p. # 7-1).*

Due to the nature of the study that focused on primary family caregivers, all participants were close relatives of their patients. However, of importance is the way participants emphasized the closeness of the relationship by using terms such as, 'blood is thicker than water', 'my sister's from the same womb', 'from the same mother', and 'it is a blood brother' to convey their commitment to looking after their patient. It implies that for people from the same mother there is no compromise, one has to do it. Although the following example pertains to other relatives supporting the patient, it serves to drive the point about the importance of blood relationships. Two rural participants (co-primary caregivers) talked of their father, who was a single child, and his half brothers and sisters from his father's other wives, and how these uncles and aunts were not supportive. Their reason for lack of support from these relatives was because the uncles and aunts did not have the same mother and father with their father.

While some participants felt that the closeness of the relationship mattered, most of them referred to incidences that showed commitment to support relatives other than



own children or siblings. One good example is that of a participant that had come to Harare to look after a sister, living her children in the rural home under the care of a mother-in-law, who also had the responsibility to look after her own mother in a village close by, that had suffered a stroke. This participant's husband deserted her, and she was living with the mother-in-law just so she could have a home for her children, but still, she had a heart for other people.

*I am a helping hand with general chores around the home, especially now that my mother-in-law has an illness in the family...She takes turns to go and look after her mother, and I also have to stay behind looking after the home, you see? And I am also looking after two children from my sister-in-law [i.e. husband's sister] that passed away last January....You just have to be strong. Because you also have children there...you just have to care for the other children...You cannot just bath your own children, and ignore those from the diseased sister-in-law.... It's now our duty to do what? To look after them, (Urban p. # 12-2).*

Another participant, HIV+ herself, rented a room in which she lived with her husband and two children, but still had room for a niece (whose parents had died) and a younger brother that both moved in after the study had commenced, despite the fact that they were both unemployed.

*I am helping my sister [i.e. niece], right now she has no parents. I brought her here to live with us. If we have to go overnight without any food, we will do it together, if we manage to eat something, that's it.... Then there is my other brother, the lastborn [in my family]. I also live with him here. He sleeps at my parents' home, but this is where he has his meals....If I could afford it I would wish to help even more of them, (Urban p. # 7-10).*

Participants also received support from other relatives, not necessarily those very close to them. For example, one participant talked of her "...mother's younger sister's children [that] used to come around and offer...[her] support," (Urban p. # 5-6). Another good example is that of a participant that used to receive support from her mother's sister's daughter.

*Our mother's older sister's children also visit sometimes. One of them works in Kwekwe. She either comes or sends money through the post office, saying, "My young sister, the last time I was there the situation was [not good], so I have sent this money so that you can use it for whatever you need...buy ...[patient's son's name]'s mother this and that." Failing this, she sometimes sends groceries. These are supportive people, (Urban p. # 11-1).*



There are other subtle dynamics that put little twists into relationships such that some relatives appear closer. For example, the participant quoted above (11-1) talked about her mother's sister's daughters, and she referred to the one most helpful as a 'sister'. In *Shona* culture there is no word for cousin. Usually when one says 'sister' and they think it is important for you to know, they would go ahead and describe the nature of the sisterhood, such as 'my sister from my father's brother' or 'my sister from my mother's sister'. The same goes for 'brother', and other relationships. The participant before her (i.e. 7-10) also referred to her niece (i.e. brother's daughter) as a sister, simply because in *Shona* culture, a niece could potentially go and be a second wife to the same person married to her aunt, or get 'offered' to the aunt's husband if her aunt should die. The offer is extended mostly to a son-in-law with a good track record with the in-laws. Also, in-laws would tend to allow a niece to get married to an aunt's husband whose track record was good. Another example of these adjustments in relationships is that of a participant whose mother had long died, and was now dependant on surrogate mothers. When I asked her if she got along with her maternal relatives, she said:

*Yes, my mother's brother that I talked about, and my mother's brothers' daughter, because these are now my mothers since my mother is late. So, whenever I meet with a problem I go there and say, "Mother, this is what has happened," and they help me, (Urban p. # 6-12).*

Because of the communal nature of the society the participants are part of, neighbours are also considered as relatives in some cases. For example, one male participant that indicated that he supported his neighbours without having to be asked, said, "No, you just know that on your own...because your next door neighbour is your relative," (Urban p. # 15-5). However, the most important aspect of this communal society that has strong ramifications for support provision is the traditional concept of totemism.<sup>13</sup> Therefore, wherever one chooses to settle, either by marriage or relocation, finding someone, a neighbour or friend with the same totem usually transforms the relationship to that of relatives. Although the relationships would be called 'distant', some people are quite serious about them.

Given such a scenario, we would certainly expect bonds of kinship to develop between people with the same totem, as well as obligations to help one's 'distant kin'. After asking one participant if there were any other relatives that supported her, she said,



"...our sister-in-law ('muroora wedu'), she comes to give prayers for the patients," (Urban p. # 10-1). After I asked her if she was a sister-in-law on her sister's, or brother's side, she said, " She is a sister-in-law by totem, and mutual respect. We call her daughter-in-law, and I am the aunt." Another participant indicated that she received emotional support from a grandmother, and, on asking how they were exactly related, she said, "I call her grandmother [because] she comes from my mother's clan," (Rural p. # 7-1).

Apart from having a common totem, some 'distant relationships' that also formed the foundation for supportive interactions benefiting caregivers were those that came from the same rural/home area as the participants. This was common with urban participants who, unlike rural participants, settle in places (i.e. suburbs) not surrounded by close relatives.

*[T]he one that understands my problems more is this one here [pointing at neighbour's house behind hers], the one that calls me sister-in-law ('muroora')....We come from the same rural area in Mutare. I call her husband brother ('murume wavo ndinvati bhudi'), (Urban p. # 2-3).*

*There is someone we call uncle (sekuru), on my wife's side...They come from the same rural area. But I...never asked exactly how they are related... (Urban p. # 9-8).*

*My brother from my home area... (Rural p. # 3-1).*

Apart from these supportive relationships based on rural origin, other supportive relationships had a basis that was not easy to determine. But it was clear that these were also distant relationships.

*There is someone that we call uncle....It's some relative o my father's side, but I am not sure of the nature of the relationship... (Urban p. # 1-7).*

*She is also a sort of sister. My husband and hers call each other brothers, (Rural p. # 4-1).*

*Deviations from the social rules:* - The many different social reactions to AIDS, PWHA and their caregivers do bring a twist into the rules of giving and receiving as indicated in an earlier discussion. In that discussion I made note of the fact that most participants tended to want to know what the patient was suffering from before offering their support. A decision to support, thereafter, depends on the nature of disease. In this section I will focus on general deviations from reciprocity norms, as well as deviations



from obligations to help kin. These are deviations that might have been caused by social reactions mentioned above, but the link is not clear. The selection of deviations from the norm that have negative consequences for support provision was deliberate as well as driven by the data at hand.

There was a general feeling among some participants that, "...these days there aren't many people that want to hear about problem's in other people's homes," (Urban p. # 10-1), and that most relatives were giving problem-focused support. This is a major deviation from the traditional, ongoing support from kin networks. Most participants, therefore, thought their relatives were not as supportive as they should. Yet, according to one participant, whose sentiments might have been representative of all the participants':

*My thinking is that, when people are from the same father and mother, they wont let each other down to that extent, (Rural p. # 2-1F).*

One participant talked about an uncle that only helped when there was a crisis.

*But that is when we ask him, like at a funeral, when he has to stand is as the father of the family; not as a father who is [always] there to help... (Urban p. # 12-2).*

Another participant, whose sick husband's parents had both died, talked about her husband's only remaining uncle that lived in another suburb, about 30 minutes drive from where they lived.

*[W]hen he last came here, it was only because one of his nephews, his sister's child, had died. That is when he came, since 1996, (Urban p. # 13-3). [My emphasis]*

The funeral that the uncle had attended was in a suburb close to the participant's home, and she considered the visit was made because the uncle was just passing through. A similar story is that, "[t]here months can go by before any of father's relatives sets their foot here to see how we are doing," (Rural p. # 5-1). Most of these many uncles and aunts, from a polygamous father, only lived either a stone throw, or a shouting distance away from the participant's home. While other relatives were reported to visit caregivers and their patients and sleeping over, as well as visiting patients in hospitals, one urban participant with two patients said that her husband's relatives were "...not supportive at all" (p. # 3-4).

*Never, the only time they went to see him [i.e. in hospital] was the day he got discharged, because the hospital was not going to discharge him if there was no one in charge. So that was the first day they ever went to*



*see him...From the hospital they went straight to their homes, and he got home alone. Since home they have never set foot here, (Urban p. # 3-4).*

Another participant whose mother's brothers and sisters were not forthcoming said:

*[As a] child...I am giving them the chance as the uncles and aunts to think, "Our relative [i.e. sister] is sick, and we must support accordingly." Look at the incident when mother fell, I am the one that rushed from my house in ... [street] ...to give her help. But since they are her relatives, and I am only a child, I would expect them to do something but they don't...I have no one to hear my cries... (Urban p. # 14-4).*

An assertion made by one HBCW, therefore, seems to support the observation that relatives are less supportive these days.

*Especially when it comes to relatives, there are very few of them that are supportive. What I have noticed is that neighbours are more supportive than relatives, knowing clearly that the person is sick with AIDS, (HBCW5).*

Another deviation from the norm concerns perceived diminishing support from young male relatives after they get married, due to the new wife's influence.

*Even these brothers, if they say that they want to support this relative [sister] of mine, [my] sister-in-law ('muroora') immediately tells him, "We have no money for school fees for the children, my dress is torn, and this child needs this and that." So it becomes difficult for him to make a decision to help... (Urban p. # 12-2).*

The same participant also showed concern that her sick sister's first born adolescent son that was very supportive during that time might change his ways once he got married.

*With sons, once he gets married everything changes. The wife will start feeding him with anti-family talk... (Urban p. # 12-2).*

Another participant whose brother was generally supportive, and had footed the sick sister's hospital bill and given the participant ZW\$200 for other expenses said this of her brother:

*But these are people whose support I do not very much put my hopes on. You know, when men get married there is the woman beside them. So, you begin to see that things are not the way they used to be [laughs] ... (Urban p. # 14-4).*

Apart from deviations from the norms of supporting kin in general, there were also some deviations from the norms of reciprocity that were reported by participants. For example, one urban participant said:



*I am one person that is very supportive of my relatives and friends, but what do you see in the end? They do not return whatever favour you will have done yourself ('...but in the end iwe unoona kuti chii? They do not return zviye zvawamboita iwewo'), (Urban p. # 2-3).*

Two rural participants, siblings, whose father used to look after his half sisters and brothers whenever they got sick, also believed that these relatives' inability to support them through their father's illness was a gross deviation from the norms of reciprocity. Each time the father helped his kin, he "...would finance them to go to the hospital, and to buy food and other things," and if the patient happened to be female these young participants would help to look after them, seeing to it that "...you have bathed them and washed their clothes," (Rural p. # 2-1F). Due to the inability of the relatives to return the favour during their father's illness, one of these siblings totally refused to believe the proverb 'Kandiro kanoenda kunobva kamwe' was a true reflection of reality:

*Because if it were like that, we would also be getting support from those we used to support. So, that is what we used to think, that those we used to help would also help us, (Rural p. # 2-1F).*

A poignant example of a mismatch between support provided and support received, one spanning two generations, comes from an urban participant that was looking after a sister, without much help from close maternal and paternal relatives.

*I wouldn't know what makes people do such things, but it didn't start today. When mother was involved, we didn't get any help. When it came to father, my father stroked, and was ill from 1993 and died in 1995. Only us, his children faced that crisis. So, I am not surprised right now that we are all alone in this one... [My parents] underwent a long period of looking after other people, looking after relatives from both sides [mother's and father's side]. Because of that they grew up with a very big family of relatives. My father used to be contracted to do painting jobs...you see, living a good life in Highfield suburb....He got blind, I don't know from what. That is when he sold the house in Highfield and we came to Chitungwiza. So, as soon as poverty came, what did relatives do? They dispersed....Relatives only come to pass their condolences on the day of the funeral, and then go...[N]one of my young brothers ever received any money for school fees from our father's younger brother, or his wife. It has always been us struggling through this. Us, the older ones would see to it that we have bought school uniforms and paid school fees, until they finished their 'O' Levels [High school]....[later] I still remember my father raised my aunt's children, sent them to school and trained them to do painting. Right now these are the jobs they are surviving on, but they never came to father's funeral; and since 1995 we have not seen them....[later] It's not all people that are like that. I am talking about my relatives...Other people support each other, (Urban p. # 12-2).*



According to this participant, her family was not the typical family where close kin supported each other. The behaviour of her relatives was a deviation from the norms that guide the exchange of support.

*Negative interactions:* - Earlier on I talked about negative interactions between caregivers and patients. Here I am concerned about interactions between caregivers and other people close to them. Almost every participant reported a particular incident or interaction between himself/ herself and other people, or between other significant others, that jeopardized the flow of support in aid of their caregiving responsibilities.

Some participants were in a situation whereby their relations with other kin were rather strained, for various different reasons. For example, I had one participant tell me, "We do not get along well with the relatives on my mother's side ('hatinyatsowirirana, hatinyatsodyidzana')," (Urban p. # 10-1). Another participant that indicated she was in a similar position also talked about how they did not get along with paternal relatives as well.

*[O]ur maternal relatives gave us a horrible ill treatment when our mother died. She woke up dead one morning, at her rural home in...[and] her brothers demanded ZW\$5,000, because they were suspicious of the way she had died.... [W]hat they did caused us a lot of pain...at the funeral, and that made us lose interest in them, because they never offered any help with mother's burial. From then on, there was never anybody that put us in their heart," (Urban p. # 12-2).*

According to this participant, both her parents were not in good books with their relatives, especially on the father's side. The only remaining younger brother of her father was the one that would help when they had a crisis.

*But that is when we ask him, like at a funeral, when he to stand in as the father of the family, not as a father who is there to help...His children sometimes come, but the times are few and far in between....[later] Right now we have to look after each other as siblings, (p. # 12-2).*

Other types or negative interactions involved in-laws, and threatened the economic welfare of the patients. For example, one participant talked about how her sick sister's mother-in-law started scheming to get her deceased son's pension (and other benefits) from the company he used to work for. Interestingly after her son's death, she had never made a follow up to see how her daughter-in-law and grandson were doing at the participant's home. This resulted in the company giving the mother-in-law money that



was intended to go towards the medical expenses for the patient, which she never forwarded to the participant. When this came to light, the mother-in-law took the patient's son with her, with the hope of securing all the monies intended for the patient and her daughter.

*There came a point where they wanted to take the property from....'s [patient's name] and her husband's home, in order that they could put some tenants into the house....The company eventually called relatives from both sides, and told them that the benefits would go towards ...[patient's name] and ...[patient's son's name] ...So it was a big blow to them, and that is when they came here...shouting at us, "You people are thieves, you want to steal my son's money. I am the one that gave birth to him," etcetera, (Urban p. # 11-1).*

After the participant let her know that she was now aware that all she cared for was money, and not the lives of her daughter-in-law and grandson, and told her she did not want to start a war with her, she left and up to the time of the study she had never been back to check on the patient and her son. Another urban patient also experienced a similar friction with in-laws. Here is what the caregiver said about it:

*1998 is when she fell sick, and her condition was made worse by thinking too much, because when her husband died there were problems concerning property. They did not have a marriage certificate or anything, they were just co-habiting. So the parents wanted to take away the house from her. They also wanted to take their son's pension, and it took a lot of effort for the money to be released. She had to look for lawyers and other...people to intervene. So, [securing the monies] took a long time while she lived in poverty ...By the time the money came she was already a patient. The condition was therefore made worse by the mental stress coming from the harassment from her in-laws, (Urban p. # 12-2).*

Other interesting aspects of negative interactions concerned close relatives that purposefully and intentionally told would-be support providers to withhold their support. One pertinent example is of an uncle that stopped his children from supporting their cousins.

*That uncle of ours [father's younger brother] ...told his children that he does not want them to help our family in any way. They sometimes come, stand there, and after seeing the patient they just leave. Since she became ill, they have never done anything to support the patient. We get support from our other relatives, (Urban p. # 11-1).*



Another participant that had a similar experience had her father and mother-in-law stop other relatives from giving support to her and her sick husband. Although these relatives were supportive, she said:

*[T]he most important hindrance is fear, they are afraid of the patient's parents, because sometimes they tell people he [i.e. sick husband] is not here, when in actual fact he will be here...Even those that go to my mother-in-law's house first, they get turned away. They get told that there are no people here, (Rural p. # 6-1).*

Because of the in-laws' behaviour, the participant indicated that there were "...only a handful of relatives [that were supportive]," and "...some [had] to wait until darkness ha[s] fallen in order to bring...things," (p. # 6-1). Another example is of a sister-in-law that allegedly told the patient's son not to help his mother because he would contract AIDS.

*With sons, once he gets married everything changes. The wife will start feeding him with anti-family talk, "Leave these things alone, this is 'a disease' ('aaa, iwe, siyana nazvo izvi, chirwere ichi')." ...because these last few days there were some people that were feeding him with some information, that "You are now going to contract the disease from your mother if you keep on doing what you are doing." ...[later, Were these friends?] ...Friends? Sisters-in-law, you know how they are, their ways, these African daughters-in-law ('Varooraka munongovaziva, maitiro avo, vechibhoyi'), (Urban p. # 12-2).*

Upon further questioning it became clear that the sister-in-law that was alleged to have told the patient's son to stop helping was the caregiver and patient's brother's wife. The derogatory reference to 'African sister's-in-law' was a sure sign of this participant's level of anger. Her mind was also far-sighted, for she foresaw her sister's adolescent son getting into a union with someone that would influence him to forsake his kin.

Other common negative interactions involved housing tenure. One HIV+ participant that was earlier forced to move out of a family home by a half brother because of her serostatus, also talked about another altercation in which she advised her mother that was living in the rural areas to move some stuff out of one room and put a tenant in. This was necessary in order for her to be able to pay electricity bills, which had been accumulating without due attention from the brother. This riled the brother, who then came to confront her.

*When he came over he shouted at me, accusing us of making such arrangements. He was shouting, "I will stand alone, because I have my*



*own mother," this and that...He said a lot of things, which is something that bored me, and up to now he hasn't set foot here, (Urban p. # 7-10).*

Another negative interaction involving housing was that of another urban participant that was currently living in a neighbour's shack. Two tenants, and her sick brother occupied the main house that previously belonged to her parents before they died, while she lived in the shack with her sick husband. When the brother passed on, she thought this was an opportune time to move into the room that was being used by her brother.

*[B]ut they [i.e. uncles, mother's brothers] are saying that there is money that needs to be paid for the house's rent, plus the money that was borrowed for the funeral. So they said that I should keep living in the cabin [i.e. shack], or look for planks and build our own...outside there....Then a tenant moves into that room so that they can pay off what is owed for the house, as well as pay back the people they borrowed money from, (Urban p. # 3-4).*

A somewhat related but different example involving housing tenure was that of two rural co-primary caregivers who spoke of their 'grandfather' [i.e. father's mother's brother] that sought to evict them from the home they had occupied for more than ten years. Apart from ordering the participant's nephew that was helping the male caregiver to care for his sick father "...to go back to his home..." so they could "...look after..." the patient themselves, which they never intended to do, they also sought to evict this family from their home during the hardest of times. This was a few months after the participants' mother had died. Since the family's fields had already been taken over, they had not planned anything by the time of the study.

Relatives that had no respect for the living and the dead caused other negative interactions. The uncle that I discussed above that told his children not to support their cousins ordered the participant and her brothers never to bring the patient's body for burial to their rural home. He told them this before the patient had died.

*And this uncle [father's younger brother] is a problem ('ivava vanotinetsa'), and right now we are not getting along. He is saying they don't want to see ...'s [patient's name, i.e. her corpse] at home there, that she must go to her husband's home ('ngaaende kumusha kwemurume wake kwaakaroorwa'). Even after many discussions with him, it seems we have failed to reach an understanding. So what we have eventually agreed upon, my brothers and I, is that, ...if God should decide to take her life, we are not going to take [name of patient] into anybody else's home [i.e. to lie in state], she will be going into the stand*



*left behind by our father....Because we are the ones who are going to bury [name], her brothers, since her in-laws are not coming.... She is not going to be buried here [in town].... If things should come to a head, we will just tell him the truth, that our father left a home, and we have come to leave her in her father's residential stand, not yours....[later] I think he just wants to fix us, to show us that he is the father and we will have to kneel in front of him. That is what I see in him... (Urban p. # 11-1).*

Despite the fact that the uncle talks about the patient having to be buried where she was married, which is a legitimate claim in *Shona* custom under normal circumstances where the in-laws are cooperating, one gets an uneasy feeling that the uncle might have been doing this because of other things, such as the nature of the disease the patient was suffering from. Although this uncle was referring to the issue of death in advance, in a related case, relatives spoke ill of the dead after the fact. These were uncles (i.e. mother's brothers) that had never given any meaningful support to the deceased or his caregiver (sister) before the death.

*I just think that maybe they don't care about me. Maybe they just think, "Well, these are our brother-in-law's children, and we have nothing to do with them ('Vanongoti, "vana vemukuwasha, hatina basa navo ava',)" At the funeral they were actually saying that they were not supposed to bury him themselves, that "prisoners should have buried him, because he didn't treat others well. He had a foul mouth. But, realising that the whole world would laugh at us, we looked around for money so that we could bury him," (Urban p. # 3-4).*

My last example of negative interactions that minimised the flow of support concerns an urban female participant that was in a raging divorce battle with her in-laws at the time of the study. On our first visit, with the outreach community nurse, we found her already packed, having been told to go by the sick husband. The husband had the support of some of his relatives, including the mother. Realising the consequence of this move to the well-being of the patient, the community nurse and I did our best to bring a common understanding between the two, and she stayed. Each subsequent visit I made for the interviews, this issue always took first priority, as unavoidably got drawn into it as a neutral arbiter. As a result of this skirmish, the usually supportive brother of the participant decided to withdraw his support.

*[M]y brother used to help me, but because of these words [arguments and divorce threat] that came out, he lost interest ('akabva ashayawo rudo') and he said, "Right now you are killing yourself selling at the market [to*



*support him], and they go about talking bad about you, and causing problems for you instead ('wonetswa ndiwe'), so I am not going to give you even the money." And he [i.e. brother] thinks I should go back to my parent's home, but I cannot imagine leaving behind my partner like this, it bothers me, (Urban p. # 6-12).*

In *Shona* custom, when people divorce, someone has to accompany the wife back to her parents in order to present the issue diplomatically, the same way the union started. In this case, the mutual female friend of the participant and the patient that had accompanied her back to her parents at some point also cut her ties with the participant.

*Other people come and say a lot of things, such as that family friend of ours that had accompanied me back to my parents' home...[W]e used to be very good friends, but right now, considering that incident, isn't it she is the one that accompanied me? After the matter was settled she has never been here.... [But] ...when he [the patient] used to have sores in the mouth, she used to come and clean them. But now with all these stories coming out... (p. # 6-12).*

This conflict also seems to have embroiled most members of the family, estranging the caregiver in the process, thereby compromising her dedication and performance.

*The way people were talking, saying, "She should go. She is not looking after the patient well." Saying all those things, and yet there is not much support that they give me. I go to the market to sell in order to get money to buy food to come and cook for my husband...coming back [at night] ...And if you happen to have a misunderstanding between the two of you [i.e. husband and wife], just like our current misunderstanding, the people here never take time to understand the issues. They just rush to send someone packing...They have limited understanding...[later] [T]hese things started around the time the sisters from Mashambanzou started coming, because when they came for the second time they brought with them cooking oil and beans. My in-laws just received those things and put them in their house. I never asked. I just left the issue like that,*  
(p. # 6-12).

On subsequent visits, the outreach community nurses handed over the supplies to the caregiver, who had her own room (cottage) with her husband, and this might have started the whole fight. On my final visit, I found the caregiver gone for good. She had succumbed to the pressure.



## The Actual Types of Supports for Caregivers

This section deals with the various types of supports that were reported flowing from network members (including kin, friends, neighbours and other people in the community), the government, and non-governmental organisations towards caregivers and their patients. The flow of these supports are indicated (in *Figure 2*) by: the arrow pointing to 'Community' from the government, the arrow pointing to 'Community' from non-governmental organisations, and arrow 'e' from Community to caregivers and PWHA. However, at this juncture it is paramount to set the stage from which to view the support flows by looking at the support needs of participants, and their definitions of support. After looking at the support flows, we will then take a peek into the caregivers' *lifeworld*, by looking at phenomenology of support receipt, that is, what participants feel about these flows, which, in social support literature is called appraisal of support.

### Support needs

The following are the common major items identified by participants as necessary to enable them to carry out their caregiving responsibilities effectively, as well as make their caregiving burden lighter: money, food, soap, blankets, gloves, disinfectants, and transportation. Although some participants mentioned money and other items as though they were of equal value, others categorically stated that money was more important because it afforded them the opportunity to buy everything else.

*For anything to 'move' one needs money [laughs]. If you get sick, you will need medication...And...money for transport. So, what one needs is money, such that you can rush your patient to the hospital for treatments...Therefore, if you have the money you can go and buy whatever he patient wants, but if...not..., there is nothing you can do, (Urban p. # 7-10).*

*For looking after her, all I need is money, because these days life is moving on the wheels of money ('hupenyu hwemazuva ano hurikufamba nemavhiri emari')...[F]or you to go to the hospital, you need money, the soap you use to wash clothes for the patient needs money, the food you give her needs money, that is the only major problem. [T]o...look... after a patient well, you need to have money within your reach. If there is no money... you have nothing to cook for them, you have nothing to bathe them with, and you don't even have a good place [in which] to care for them, (Urban p. # 12-2).*



*The support I wish I had is support that would enable me to buy food for her to eat, (Rural p. # 1-1).*

There was no difference in the need for the resources mentioned above between urban and rural participants. The interviews with HBCW in both sites supported the findings of the interviews with caregivers. Based on their experience of working with caregivers of PWHA, they also identified the above-mentioned items as the ones that caregivers had problems finding.

There were fewer participants that indicated that they would need informational support, or knowledge, in order that they carry their caregiving role more effectively. Those that needed information or knowledge wanted information on: the right types of foods to give to their patients, how to feed their patients, 'how to better handle a patient'.

*What I might want help with is, if there could be some knowledgeable people such as you who could come and teach us so that I add on to the little that I have, (Urban p. # 13-3).*

*[T]he reason you saw us going to sister...[name of HBCW] was so that she helps us with knowledge. Because if you just sit at home you wont know anything, [but] if you go to others they can teach you...Then you are able to help because you have the knowledge...[I need] to know how I can help her when she is sick; let's say she has messed herself up, [I would need to know] how to handle the things, how to wash the clothes. Others just talk about gloves and other things, and you might just think they are lying, and you end up doing your own things...That is the information we wish we could be helped with... [Also] what foods she must be eating, or how you might gain access to helpful resources. These are the things I wish I had someone to tell me, (Rural p. # 7-1).*

Although many participants at one point or the other mentioned the importance of emotional support, only one mentioned it as a resource she would need to get help with in order to cope well with caregiving responsibilities.

*Having people that console me, because there are times when the situation becomes so difficult... (Rural p. # 6-1).*

Few other participants, all of them urban, indicated that they would want help with resources to start income generating projects.

*If I could get some money, I would use it to buy some items, which I could sell, to get more money to buy some of his favourite foods, (Urban p. # 3-4).*



*[Some]times I get really frustrated and wish I could get something I could do while at home...If only someone could help me start some income generating activity that I could do while at home...so that I can spend more time with my patient...For example brickmaking, or tying and dying clothes... (Urban p. # 6-12).*

*If I could find some capital to do an income generating project, I would buy more books to add to my stall, or buy second hand clothing for sell, so that I can support myself, because there is nowhere you can go asking for money day after day, (Urban p. # 7-10).*

What most participants wanted help with, therefore, were resources to meet their most basic needs. Those that had income generating projects in mind had in mind resources that could make them self-sustaining.

### Lay definitions of social support

There is no *Shona* equivalent of social support as it is defined in Western literature. Asking participants what social support meant to them, therefore, involved a long-winded explanation combining the words 'support' and 'help' ('kubatsita/ rubatsiro'). However, the downside of using the word 'support', was that most participants equated it to "...provid[ing] someone or something with the means necessary for living or existing" (Chambers 21<sup>st</sup> Century Dictionary, 1999). This comes as no surprise, because even illiterate people use the word, in its English form, to mean what is said by the above definition, and much of the influence comes from cases whereby absent fathers, or one of divorced parents (usually the father), send money for the upkeep of their children or former spouses. This scenario, therefore, might have coloured the participants' responses to the question asking them what 'support' meant to them. However, to mitigate its effect on their responses to a request to name the types of supports they got from organisations as well as from network members, I explained to them what I wanted them to focus on when they answered that question, as well as when answering related questions.<sup>15</sup> Together with my explanation, I also gave a few examples of each of the functions of support (viz. emotional, instrumental, informational, and affirmational).

These are some of the definitions participants gave:

*Support is being given food, and things to use, (Rural p. # 1-1).*



*People that come and give us things [meant for the patient], (Rural p. # 2-1M).*

*Someone that is looking after you so that you can survive, (Rural p. # 6-1).*

*Support is helping each other ('kubatsirana')....[with] food, or money, and maintaining someone (Rural p. # 2-1F).*

*Being helped with things....[such as] money, food...[and] clothes, (Rural p. # 3-1).*

*Support is the help we get from other people....[such as] food to eat, clothes...Rural p. # 5-1).*

*Supports are things given to you to help supplement what you already have, (Rural p. # 8-1).*

When I asked participant 2-1M to elaborate, he gave the example of someone 'coming to help [them]' or just "spending the day together, and helping me do the work I will be doing in the afternoon." Although he made reference to being helped with work, which is instrumental support, 'spending the day together' might be interpreted differently, to mean moral support, which is emotional support.

The best definition, with an all-encompassing array of examples that covered the four major functions of social support was given by a female rural participant, who said social support is, "Those that help you when you have a burden, so that it becomes lighter," (p. # 4-1). She went on to say:

*One might help you with plain words. One might help you with money, saying, "...you can buy your patient whatever he wants to eat." By doing that they have helped me. One might say, "Oh, my love, it doesn't matter, God knows. He is the one that looks after him [patient]." They have helped me calm my thoughts ('andibatsira mazwi ekufunga'), so that I don't get worried. That is support to me. I remain peaceful [when they go], knowing there are people that are consoling me, that there are people that want to help me looking after the patient, just through words, (Rural p. # 4-1).*

Congratulating her on giving such a well thought out response, as well as alluding to her earlier comment about her perceived inability to be a good participant because she did not go to school much (Grade 2), I reassured her by saying the following proverb to her:

*You have hit the nail on the head ('mabva mabaya gudo nemukanwa') [laughter from both of us]. You can consider yourself a Grade 7 graduate proper! [more laughter]. [in jest] We should consider giving you a certificate [more laughter].*



Although this participant had not given examples encompassing all the support functions, she was the only one that had moved beyond equating social support to material support. The importance of emotional support was well articulated.

Another important variable that might have influenced participants' definitions was their present state of deprivation. Given the prevailing macro economic situation then, and the participant's material circumstances, it is understandable how one might put emphasis on instrumental support. Looking back into the previous section on the support needs of participants actually confirms this link. The other three functions (viz. emotional, affirmational, and informational) might have been relegated to a lesser important status, as higher order needs, due to the pressing day-to-day bread and butter issues to satisfy basic needs. Such a bias came out clearly in most discourses. Participant 6-1, who said that support is "someone that is looking after you so that you survive," presents a good example. The word survive, on its own connotes a desperate situation from which one needs to be rescued with social support. She went on to say:

*Mostly being helped with my child's school fees, so that she goes to school and not sit at home, and getting the food that my patient wants, and money for hospital fees. These are the things that I have difficulty with most of the time. Food, hospital fees and my child's school fees, only... I...think... "Will I manage" or "Where will I get them?" (Rural p. # 6-1).*

Another participant whose response showed a similar bias, or inclination towards satisfaction of immediate, and pressing basic needs said:

*The other many things you can include are, when someone gives you soap...you know that these days no one can just give you something. Things are difficult. If you say to someone, "Can you help me with this?" they say, "Isn't it you see what the situation is like? There is nothing I can do. I also do not have anything....[later]....Yes, that is the biggest problem we face...if you can find someone to send your children to school...because all the other things around the house you can just manage to solve on your own, especially the small things.... As well as children's clothes, and blankets; that is all support. Those are the things that we have problems getting, (Rural p. # 7-1).*

Yet another participant also qualified her definition by a statement that highlighted the areas she had problems with in life.

*Things such as food, school fees, and hospital fees, which are usually problematic, (Rural p. # 8-1).*



This bias towards instrumental support will be revisited when I discuss participants' appraisal of the supports they were getting. Despite mentioning the importance to their day-to-day functioning of other types of supports they were getting, most participants pressed home the importance of material support. First of all, we need to know what supports they received from various organisations and network members.

### Formal Supports

Formal supports were those supports that participants were receiving or had received from any formal organisation, including the government, and non-governmental organisations. The flow of resources from these organisations is depicted by the two horizontal from the left and right side of *Figure 2*. Due to the nature of the research, whereby recruitment of participants was done through these organisations, most of the supports reported in this section were received from Mashambanzou Palliative Centre, Red Cross of Zimbabwe, and Mother of Peace Orphanage. Although no recruitment was done through government institutions, all caregivers' patients had at one time or the other visited a government hospital or clinic. Therefore, 'government', with its overall responsibility for the welfare of the nation, automatically qualified to for inclusion in *Figure 1*. Some other participants were, or had received supports from other non-governmental organisations, as well as religious denominations they belonged to.

Instrumental Support: - Instrumental support includes all kinds of material supports, including the actual care given to the patient, respite care and other services. Due to the fee-for-service nature of health services provision in Zimbabwe, most participants did not recognise the services their patients received from hospitals and clinics as part of social support. Others might also have failed to recognise the services as support because of the nature of the disease, which cannot be cured. Therefore, the fact that the disease continued despite the assistance might have signified 'no assistance' to these caregivers. Related to this is also the fact that patients with AIDS are released to go home so that they receive home-based care. With the majority of participants probing was essential in order to solicit the support they had received from a hospital or clinic as illustrated by this dialogue:



I: In this programme, what we mean by support are: the assistance you get from hospitals, clinics, the government, the pharmacy, neighbours, friends, relatives. Whatever you get from anybody on a day-to-day basis as well as to make your caregiving responsibilities easier is included. Moreover, by support we are including things like money, food, and a listening ear so that someone can share your burden or offer you comfort, ideas or information; all these are supports. So keep this in mind while we talk. Let us start with support from the hospital or any organisation that might have assisted you.

P: *I haven't received any.*

I: What about those at the hospital, how do they support you?

P: *I haven't received any from them.*

I: How about the two times when you went with the patient, you never received any help?

P: *I did not get any help.*

I: Maybe we are not understanding each other. If you go to the hospital and you see a doctor or nurse and they say you can now go and buy your medicine, that is also help. We do not only mean things you get for free.

P: *Okay. I went and she got examined and they asked for her saliva sample, which we took in after two days, then they gave us a prescription.*

Participants from the urban sites had a variety of government hospitals and health centres (a.k.a. clinics) to go to with their patients, including the two central hospitals, and the Beatrice Infectious Diseases Hospital (a.k.a 'Nazareta' – informal) where patients with TB go for X-rays and check ups. Although private hospitals are available in Harare, only one participant reported of seeking services from one. Rural participants had access to Mutoko District Hospital. Apart from the actual treatments done for other opportunistic illnesses, the majority of participants, both rural and urban, indicated that the only major support they received from health centres and hospitals was the free medication given to TB patients.

*The only support [from the hospital] is that my sister, who has TB...gets free treatment. That is the only support I received, (Urban p. # 14-4).*

*[H]e had serious pain, and we didn't have pain-stops. Right now he is getting free treatment at the clinic... (Urban p. # 2-3).*

*[Mutoko Hospital] ...is where we got help with his treatments without paying user fees....And since they gave us the tablets, the swelling started to get better, (Rural p. # 4-1).*



*They only help me with medications, (Rural p. # 6-1)*

Those that use the services provided at the Beatrice Infectious Diseases Hospital also got free treatments, and most of the urban patients had gone through this hospital.

*We just go for check-ups, just like you know we will be going tomorrow....It is okay, because he doesn't pay anything at Nazareta, (Urban p. 3 6-12).*

A few participants reported that they received gloves to use in when tending to their patient from government hospitals. The volunteer HBCW from one of the rural sites also reported that the supply of gloves she gets from Mutoko hospital for distribution to caregivers was very erratic and inadequate. Although much of the support described here, particularly free treatments, might seem directly related to the patient, except for gloves, one participant's view does shed a different view:

*There is a question you asked me last week...about whether the help is directed at me, or the patient. And I said the support involving medications is directed at the patient. But I later realised that is not the case, because I am the one that was going to buy the medication. I was going to look for the money to buy the medication. I was going to face that problem. So...that kind of support is directed at both of us, (Urban p. # 6-12).*

The material support indicated by the arrow labelled 'Funds to AIDS support groups' in *Figure 2* was deliberately made thin to indicate its inadequacy as well as its skewed, urban biased distribution. Despite the availability of millions of dollars that had been collected from taxpayers by the time of the study, only one urban HIV+ participant indicated that she was part of a support group that had just received funding. Among the rural participants, news had just reached them that they had to come together into support groups and initiate project proposals in order to get funded.

Apart from government facilities, one of the two urban sites (Chitungwiza) had participants that received support from The Zimbabwe Red Cross. However, of the five participants from this site, only two reported receiving material support from the organisation. According to these two, this was the only organisation that supported them, besides government hospitals. This was in the form of disinfectants, some off-the-shelf medications and gloves. The supply of these items was also confirmed by the three HBCW interviewed. One of the participants always made trips to the clinic to seek new



supplies, while the other participant indicated that the pair of gloves that they were given were since torn, and they were using a pair that they had bought for themselves.

Out of the five participants interviewed, only one readily recognised what I was talking about when I asked what organisations supported them. Three of them did not even know what I was referring to when I prompted, asking 'How about from the Red Cross?' until I reminded them that the person that had introduced me to them was a Red Cross HBCW. One participant had indicated that she did not know of any organisation or anybody that supported her, apart from myself, who had given her a pair of gloves, a disinfectant and ZW\$500 as a token of my appreciation for her participation in the study. That goes to signify the lack of impact the organisation has had, regarding support for caregivers. The three HBCW interviewed blamed the erratic supply of material support and home visits on lack of funds, the reduction in working hours to four hours per day at fortnight shifts per person.

The organisation that was seeing to the welfare of participants and their patients in the other urban site (Mabvuku) was Mashambanzou Palliative Centre. This organisation offered the following material supports: foodstuffs (corn meal, cooking oil, dry beans, dried Kapenta fish - 'Matemba'), washing soap, medications (e.g. pain killers, cough medicines). These were supplied to caregivers about once a week or fortnightly, depending on need, as assessed by the nursing sister that headed the outreach team. Other material supports supplied to participants, but based on a need basis were: donated second hand clothes for patients and other family members and blankets. I did witness the distribution of all the items mentioned above on my introductory visit.

*[P]eople from Mashambanzou are the ones providing most of the help these days as far as I can see. They are likely to come even today or tomorrow, and drop off...about a 20 kilogram packet of corn meal, cooking oil, and, and a packet of 'matemba' (dried Kapenta fish), (Urban p. # 1-7).*

*Mashambanzou helps us with food: corn meal, beans, cooking oil, and soap for washing. And when [a] ...patient tell[s] them that they are coughing, they give them cough medicine, (Urban p. # 10-1).*

Other types of instrumental supports that were offered but infrequently include cash for X-rays and other services the organisation could not offer, transporting patients to hospitals, respite care for patients that were seriously ill, depending on availability of



beds at the centre. On my first trip with the outreach nurse I witnessed the disbursement of ZW\$600 for an X-ray and ZW\$2,000 for consultation to a caregiver whose son needed medical care. Another participant was promised ZW\$600 for an X-ray for her daughter.

*Those [i.e. Mashambanzou] are the ones helping me by taking the child to the hospital when things get worse....[later] The sister brought the money here, \$700, which we used to take him to the hospital, (Urban p. # 4-5).*

The centre also provided start-up goods for income generation for patients.

Patients were given goods worth more than ZW\$150, mainly sweets (a.k.a. candy), biscuits (a.k.a. crackers), popcorn ('maputi'), and 'centakools'. On my round with the outreach nurse I saw these items distributed to four patients. These were intended for patients to generate money in order to be self-sufficient. Patients are expected to return ZW\$100 back to the centre after they have made some profit.

*Sometimes they give me goods to sell....[later], for example this other day, recently, they left behind two cartons of biscuits. I sell them and then return \$100 to them, (Urban p. # 6-12).*

Another participant that was looking after a toddler and a sick baby, an epileptic patient himself, also reported the various types of material supports he had received from this organisation.

*People from Mashambanzou bring me tablets...if I give them my prescription. So they know how many I need per month. And they have brought us some blankets before, the ones that we are using now. I had told them that I had no blankets since my late wife's belongings were to be taken by her relatives, so they brought these blankets, as well as children's clothes. They also brought be some goods to sell so I could buy us a few things, let's say we have run out of sugar or paraffin fast. So they did this to enable me to have some money in the house all the time, (Urban p. 9-8).*

The centre also gave patients an opportunity to come to the centre to do some work (e.g. sewing) for some remuneration and their upkeep. Only one patient from those in this sample was engaged in this activity. Another type of instrumental support offered by this organisation, but through HBCW, was home visits, which involved: bathing and cooking for some patients that were looked in while caregivers went for work, and respite care.

For the majority of participants, Mashambanzou Palliative Centre was the only organisation that was giving them material support. Another appreciative participant



indicated that the only material support he had received so far was from Mashambanzou and myself (i.e. the money and items supplied for participation). Only four other participants from this suburb of Mabvuku indicated that they were receiving support from other non-governmental organisations. One of them was receiving support from the Anglican AIDS Trust once every month. This organisation supplied: part rent (ZW\$200), school fees for children, foodstuffs (e.g. peanut butter, cereals, soap, medications, clothes, money for X-rays, and medical examinations by their own doctors. This participant believed that they were getting more material support from the Anglican AIDS Trust than from Mashambanzou:

*Because the corn meal they give...lasts a month...they give us 40 kilograms of corn meal....Therefore I think we are getting more support from the Anglican AIDS Trust than Mashambanzou, (Urban p. # 10-1).*

On the other hand, another participant that was receiving support from another non-governmental organisation called Island Hospice indicated that she was receiving more support from Mashambanzou than from Island Hospice, because the former supplied "food and medications," while Island Hospice was reported to be helping patients with medications.

*They help with medications. Let's say you have gone to the clinic and you get a prescription, if they happen to have the medication they will give it to you, if you do not have money, (Urban p. # 6-12).*

Another participant that had once received support from the Island Hospice while his deceased wife was still sick also reported to have received bandages and medication.

The supports offered by the organisations discussed above, Mashambanzou and the Anglican AIDS Trust is mainly aimed at focused at easing the burdens of both the caregiver and patient. For example, one participant commented, "I would say the caregiver [benefits as well] because when they [i.e. Mashambanzou] bring corn meal and cooking oil, [the food] is eaten by everybody," (Urban p. # 7-10).

The participant that was getting support from the Anglican AIDS Trust and the one that was getting support from Island Hospice, both indicated that they got in touch with the organisations through their social networks. The other participant that mentioned another non-governmental organisations apart from Mashambanzou, mentioned the Zimbabwe National Network for PLWHA (ZNNP+). However, this organisation was reported to be "...just starting...", but there was talk that it was considering taking the



role of contributing to "the education of...children" of AIDS patients. This participant belonged to this organisation because of her serostatus.

Only one urban participant reported receiving material support as a one-off donation from a local Roman Catholic Church.

*[A]s for the Roman Catholic I went there myself, after seeing that my situation was getting worse. I went to them and talked to the priest, who visited us here, and saw our problems.... [later] From [them] I got food, a packet of corn meal, sugar, and soap to wash the children's clothes,* (Urban p. # 9-8).

As for the rural participants, apart from the little support they received from Mutoko Hospital, when they visited it, all participants reported of no other organisation providing instrumental support other than the churches they belonged to. Only three out of nine rural participants reported receiving some form of material support of this kind. One female participant that had received ZW\$40 the last time this happened explained:

*[W]hat they do, as a matter of policy is when you are a supporter ('anotsigira')...It's different from giving donations. There is what we call 'inotsigirwa' among us women....Those cards which you fold everyday. So in there, in that congregation ('chita') is where they ask people to contribute, be it a dollar each, and they put the money together. That is what they come and give to you,* (Rural p. # 3-1).

Another participant noted that Roman Catholics from her church had come the previous "...year to offer assistance with weeding," (Rural p. # 4-1). The third participant to have received material support from her church said, "At church sometimes they donate clothes once a year. Sometimes they give us clothes for the children," (Rural p. # 7-1). As the evidence shows, there are very few material supports for rural participants.

*Emotional Support:* - Emotional support given to participants by people working in various organisations (government and nongovernmental) came in various forms, including: showing concern and being understanding, empathising with the caregiver, moral support and encouragement, church services, and consoling the caregiver.

Participants that indicated that they had received emotional support from nurses and doctors were fewer. The one urban participant that had taken her patient to both a government and private hospital reported receiving more emotional support from the doctor and nurse at the private hospital. Speaking about how she thought the nursing



sister and doctor at the private hospital showed that they empathised with her, this participant said:

*She just said, "There is not much we can tell you...as we both can see... [patient's name] is in a lot of pain. She is sick"....[later] She felt disturbed ('aitobatikana'), because even the doctor himself.... said the same thing, that ...[patient's name] is in pain, and that she is very brave.... And you could see that the doctor was disturbed himself ('and uchiona kuti chiremba varikubatikana') while looking at her like that, (Urban p. # 11-1).*

This was the only urban participant to report that she had received emotional support from hospital personnel. When she talked about her local government hospital, to which she had taken her sister more than four times, she just said, "Depends, you find one that shows anger in them [one day], and you also find one that understands the problem you are facing..." (p. # 11-1).

Five out of nine rural participants reported having received some form of emotional support from hospital personnel. Three of them were speaking about personnel at Mutoko District Hospital, while two were referring to nurses and a doctor from All Souls Mission Hospital, about 100 kilometres further from Mutoko district hospital. One participant said a nurse at Mutoko District Hospital "showed concern" (Rural p. # 2-1F); while one said that a certain nursing sister had love, "...such that when mother is discharged from here, she sometimes comes home to see how she is doing," (Rural p. # 8-1). While the third participant said that all the personnel from the hospitals she had visited were helpful, "Those at Mutoko District Hospital comforted me ('vakandishingisa zvikuru') a great deal..." (Rural p. # 6-1). One of the two participants that received some form of emotional support from personnel at All Souls Hospital made the following comment: "Uhhh, but that doctor at All Souls...[name], that one is very understanding. He gets really worried..." (Rural p. # 3-1).

Only one urban participant from those supported by the Red Cross HBCW indicated that the HBCW gave her emotional support in the form of encouragement and once coming to pray with her. There were more comments regarding emotional support from the nursing sisters that distributed material supports for Mashambanzou. There were reports of participants being comforted. One participant talked about the current outreach nurse who had recently started supporting her:



*Uhhh, that woman comforted me very much. Because the first day ...[son's name] arrived from South Africa....She really consoled me a lot....Aaah, she made me control myself quite a lot, I had reached the end of my wits. A lot of thoughts were running around in my head, concerning his [i.e. son] illness...but she said, "No, people can just get sick anytime." ...She really comforted me a lot....Even this one [neighbour] talked to him [patient] after the sister had gone, and he said that he also felt comforted a great deal. Aaah! That woman is very good, ugh, she is very nice... (Urban p. # 2-3).*

When I asked this participant if anyone from Mashambanzou had empathised with her she also said, "I only know that woman you came with....moral support is what she really gave me. She gave me serious moral support, (p. # 2-3). Another participant that referred to the same sister also said:

*[She] is the only one that finds time to sit down and discuss with us...Even that time when we had a domestic dispute, you saw that she came and talked with us, and talked us out of it, (Urban p. # 6-12)*

In as much as the nurse did a lot of counselling, and giving advice to the mother-in-law, participant and her patient husband, she also provided informational support, a subject of a later discussion. Two other participants made reference to the emotional support that they had received from the former outreach nurse. One of them said the nurse "...would feel troubled..." by her problems (p. # 4-5), while one said, "...that one used to show that she was quite worried and was concerned about my life..." (Urban p. # 9-8).

Only one urban participant reported receiving emotional support in the form of words of encouragement and empathy from two local HBCW that worked under Mashambanzou.

*They told me, "Even if you used to do wrongs to each other, do not keep it in your mind. Just be strong. We know that patients are abusive with their mouths, they shout, but no matter what he says, keep a 'clean heart'..." ...and ...you could see that they felt sorry and showed a lot of compassion, to the extent that you could see they also felt the hurt in them. Even the way they were handling him in that room, I noticed that they were full of love, and that they were deeply touched by my brother's illness, (Urban p. # 4-5).*

Only two participants reported that they were churchgoers and they received emotional support from their congregation that periodically came to offer prayers at their homes.



*And there are also times when she [patient] would ask us to call the pastor to come and pray for her because she said she felt a burdened inside...So, the pastor would come and work with me. On Thursdays, he would come with the women from the special Thursday women's church services ('madzimai eruwadzano') and pray in here. And you could see that she was quite happy about that, (Urban p. # 11-1).*

This participant was a member of the Methodist Church, while the other one belonged to the Roman Catholic Church.

*[O]n Sunday they come individually, but on Wednesday they come as a group...[They come long] enough to allow us to discuss, because each one of them...has once experienced a similar problem. So they take time to talk to you, such that if your mind was going off track, it comes back on track ('kuti kanapfungwa dzako dzengedzichifunga zvimwe dzinodzokedzana'). After that they give a prayer...(Urban p. 13-3).*

While more rural than urban participants reported to be churchgoers, only two rural participants were specific about the emotional support they got from their church member as a congregation. One of the participants indicated that they had "prayers dedicated" to them, and they got "consoled", (Rural p. # 8-1). The other participant, who belonged to the Methodist Church, indicated that once her church people notice her conspicuous absence, they come about once a month to hold a congregation at her home. She described these congregations as helping to 'console' her.

*They come to comfort us. I can say those from my church are the ones that console me the most, (Rural p. # 7-1).*

None of the four rural participants that fell under the area served by one of the rural HBCW made any strong comment about emotional support provided by this HBCW, apart from saying that she offered them 'encouragement' to ignore issues of stigmatisation and continue to perform their caregiving responsibilities (p. # 6-1). However, her experiences show that she is an important source of emotional support. She indicated that when she visited affected families she felt 'pain' in her heart (p. # HBCW5). Also, being an HIV positive person herself, she gave moral support based on her personal experiences.

*Informational Support:* - Included in this category of support are things such as: dissemination of information, counselling, advice and health education. Conspicuous by its absence was informational support from hospital personnel. Very few participants



reported ever receiving information on how to care for their patient from hospital personnel. Most of the participants that said this also indicated that they had not taken the initiative to ask the medical personnel to furnish them with any information they might have needed.

One participant indicated that after taking her son to a hospital, "...he was examined by a doctor who didn't take even ten minutes doing that, and we were told to take him back home," without any explanation of how they would go and care for him, (Urban p. # 2-3). They took him to another hospital - a municipal one- and again, they were "...never told how to care for him," although they were told that he must not smoke or drink alcohol because of the TB he had. One participant indicated that they had been told by hospital personnel how to look after their father, "...how to feed him", how to keep the environment clean, and "...how to give him tablets," (Rural p. # 2-1F). An urban participant also talked about how a doctor from a private hospital explained to the family members what to expect from her sister's illness, given the nature of the disease.

Participants served by Mashambanzou and the Red Cross reported receiving information on, how to feed the patients (especially where the patients had TB), how to bathe them and wash patients' clothes, how to keep the rooms in which patient slept clean. One of the HBCW attached to the Zimbabwe Red Cross confirmed the fact that they offered health education to their clients. One HIV+ participant also spoke of the counselling they received from Mashambanzou personnel.

*They also do some counselling, which helps us a lot because people have neglected us since they have discovered about this situation, (Urban p. # 7-10).*

The same participant also mentioned that she got informational support from the AIDS Counselling Trust, where they discuss the spread of the disease "...despite the growth of support organisations, and what could be done..." (p. # 7-10).

The two participants that were churchgoers also indicated that the church offered informational support in terms of advice. This was echoed by a rural participant that also said she got "...advice on how to coexist in families and how to care for children" from church, (Rural p. # 1-1).

Rural participants reported less informational supports than urban participants, mainly due to the fact that there was only one non-governmental organisation (Mother of



Peace Orphanage) that was on the verge of trying to (unofficially) expand its mandate in order to accommodate PWHA, beyond its focus of AIDS orphans. Moreover, the other four participants lived far from it and therefore had no direct contact with the organisation. Overall, informational supports provided to caregivers by formal organisations were scanty, to say the least.

*No support from organisations:* - There were other urban participants that indicated that, apart from taking their patients to the hospital, and having HBCW pass through once in a while, particularly in the site serviced by the Zimbabwe Red Cross, they did not receive any support from any organisations other organisation and that they did not "...even know how to go about it..." (i.e. how to access these supports), did not have any "...knowledge" of these organisations, did "...not know any of the organisations." The two participants (out of four) that had registered in support groups through the Mother of Peace Orphanage also indicated that they had just joined two months before, and had not received any form of support as yet.

### Informal Supports

Informal supports are those that participants reported to have received from kin, friends, neighbours, and members of the community, including members of their religious denomination that came to support on an individual basis. The vertical arrow labelled 'e', in Figure 2, represents this flow of support.

*Instrumental Support:* - All participants reported receiving some form of instrumental supports. However, the flow of these resources from network members to caregivers can better be explored if presented as a continuum, with most of the participants falling on the 'few supports' side of the continuum, and a few participants falling on the 'many supports' side. Instrumental supports varied from practical assistance with caregiving tasks to material resources, such as food items. Material support also encompassed things like help with traditional herbs. The sources of these supports also showed a wide range, from siblings, spouses, other close kin, friends, to neighbours. There was no apparent difference between the amount of supports one received between urban and rural participants. However, the only slight difference was in terms of



monetary support, where urban participants seemed to have a slight edge over rural participants. This might have largely been the influence of living in communities where some network members were gainfully employed. Even though urban participants seemed to have that slight edge, the amounts received were not significantly high.

*They [i.e. close relatives] do help according to their means, but not hundred percent like some people do that can give you like a thousand dollars, no. But these days if someone gives you even \$300, or \$500 it doesn't help with anything. You see, it's not helping in any way ('haina chairikuita mari yacho'), (Urban p. # 12-2).*

*There are very few supportive relatives, and they are just as deprived as myself...These days a soft drink costs \$13, so one might come with just that much, (Urban p. 13-3).*

All participants that had spouses reported receiving relatively adequate instrumental support from them. All indicated that their spouses were always there for them. However, this was dependent on their access to resources, and, since all but one was not in any kind of employment, much of this support consisted of helping with other caregiving-related tasks.

*Yes, he helps me. Even helping me by persuading her to eat, or boiling water for her to bath...He helps me with everything....Things like working in the fields, even cooking, or going to fetch water from the well. When he realises that I have too much on my hands he helps me, (Rural, 1-1).*

*God blessed...me with the man I married. I don't know how I can ever thank my husband. Because I am not alone here, I have three older sisters, and among the three of us, none is a tenant ('hapana anoroja'). Each one of us has her own house. But my husband accepts this [i.e. having the patient in their house] .... When she we brought her here...even when she was still able to go to the washroom on her own...I would see my husband grab a chair...sit [besides her] there, talking to her, and maybe even peel an orange for her. Or he would take Mazowe orange crush for her, and other things. And you could see that he was doing that wholeheartedly. You could see it even in the way he talked.... Yes, my husband cares a lot ('murume wangu anerudo zvakanyanya'). For example yesterday he went around to get my young sisters ['madzimainini'] and took them to the hospital. That is support. Because if he didn't have the love he would just say, "The illness has dragged on too long." ...Therefore, I thank my husband very much, because there are others who forbid their wives to bring their relatives into their homes, (Urban p. 11-1).*



Apart from helping with some caregiving tasks that helped to make the patient feel comfortable, this participant's husband provided vital instrumental support in the form of allowing the patient to come and live in their home.

Most of the participants on the 'low side' of the support continuum reported receiving none, or very little, intermittent material supports from relatives, neighbours, or friends. Some reported receiving little support from a few close relatives. For example, one participant that was looking after three patients (with the fourth one having died four months before) reported receiving support from only one relative, a cousin.

*She helps us in many ways, because if we tell her we are short of money she gives us. Even meat, and other foodstuffs she brings us. Even when someone is in hospital she sends food there, (Urban p. # 10-1).*

This participant also reported having only one friend, whom she sometimes "...ask[s] for money...", and the friend gives her "...if she happens to have some," (p. # 10-1). Another urban participant that received relatively little material support said:

*There are no relatives that support us....I cannot count on our brothers, because they do not have good jobs, you know, the job market is not good. There is also out older sister...[s]he is married and she just manages to support her family, and cannot afford to spare anything for us, you see, (Urban p. # 12-2).*

Similarly, another participant said that although all his relatives were aware of his sister's illness, but their support provision was limited because of their circumstances.

*Most of them are not employed. They have the desire to help, but we are just in the same boat...When I do pass through their homes, most often than not I receive maybe a loaf of bread to go and feed the family, and a cupful of sugar, (Urban p. 1-7).*

No rural participant reported receiving a noteworthy amount of material support. On the 'low end', most participants reported instrumental help involving minor food items, assistance with some household chores. For example, a participant that reported that most of their paternal uncles and aunts never visited them from just a stone throw away; said only one maternal uncle was supportive.

*Our uncle, mother's brother...is the one that managed to plough for us. And he is the one that sometimes manages to give us some food, (Rural p. # 5-1).*

This participant also received support from her only friend.



*When she comes here she asks, "Do you have food here? If you have none, come with me and collect some vegetables." Her family is good at garden farming. "Lets go so you can bring vegetables and paw paws." [Mother] likes paw paws very much. "If you have no money, I can give you some money and you can come and do some work for us," (Rural p. # 5-1).*

Somewhat falling between the 'low end' and the middle of the support continuum scale were two participants that were looking after a father. The two daughters had husbands that worked in Harare, and would occasionally go to collect money for food items and other things. These were the only participants that had gainfully employed spouses in the whole sample or close relative for that matter. However, these resources were not enough, such that when they needed to transport their deceased mother's personal and household items to her home of origin, they had to borrow money.

*[W]e were loaned some money by people from the 'Society' [i.e. mutual aid organisation] father belongs to...because there was nowhere else we could have got the money, (Rural p. # 2-1M).*

Out of the nine, only one participant reported receiving what she thought was considerable support from various people in her life, including "...things to use in the home..." such as salt and other minor food items from a friend. She also indicated that relatives from her husband's side helped "...quite a lot", with "...everything, [o]ne might bring clothes, and one might bring food," (Rural p # 1-1). Her brother also helped her once with hospital fees for the patient.

*But you can just see that he is also struggling, because he has a very large family...he has three wives, and ten children, (p. # 1-1).*

Compared to other rural participants, this caregiver was in a relatively better position, but the supports she received were nowhere near a few of reasonable well-supported participants. The following urban participant reported receiving much more instrumental supports from close kin, friends and neighbours than any other participant. She had the following to say about her two brothers were very supportive:

*[W]hen this happened my brothers came here and...told [my husband], "Brother-in-law, you are the owner of this house, and we are going to help you pay water and electricity bills..." So, at the end of the month, one of them settles the electricity bill, and the other one settles the water bill. And they also buy grocery for me, worth more than one or two hundred thousand dollars. And they also give me hard cash, because any time the patient might need to go to the hospital, so they say I*



*shouldn't hard up for cash at any time. These "children" really support me, (Urban p. # 11-1).*

Her friends were also quite supportive, and she had this to say:

*They come quite often and help her [i.e. patient]. I can say with this illness I have been helped by many different people. One would come here when I was facing hard times ('ndiripanguva yakaoma'), while I was doing laundry, and they would just take a broom ('mutsvairo') and sweep the house, and another would wash the plates. All friends, (Urban p. # 11-1). [My emphasis]*

Sometimes these friends "...would come and ask what she would like" them to buy for her, "and the following day you would see those friends bringing her those things..." This participant's sisters were also helpful with providing respite care whenever she wanted to go out of the house to do other things. The sisters also helped her to bathe the patient sometimes.

*Emotional Support:* - Emotional support for caregivers originated from many sources, such as friends, close relatives, neighbours, and people they attended church with. For most participants, emotional support consisted of: showing love, empathy, words of comfort, just providing a listening ear and shoulder to cry on, visiting to check how the caregiver and patient(s) are doing, and words of encouragement. All participants reported receiving some form of emotional support from their networks. Those belonging to smaller networks also had fewer resources (i.e. emotional supports) to fall back on.

Before going any further, I would like to point out that participants received much more emotional support than instrumental support. The major reason cited by most of the participants was the prevailing economic situation that brought poverty to most members of their networks, thereby leaving them with the only support they could give, emotional support. According to one rural participant who said that her uncle had just visited her the week before "...just to see the patient..." the uncle told her, "I cannot give you any tangible help, but I ask you to put your love first," (p. # 1-1). Another rural participant also indicated that her sister-in-law (husband's sister) mostly support her "...in the manner of encouraging words..." because "...they also have problems" so they couldn't "...help her with anything else, but words," (Rural p. # 4-1). This participant also had two daughters that were down with AIDS. According to this participant, "when one is in this village there is no help they can give you, because they have no money, so if they do not



come with some, it also means they do not have at their home, so there is no way they can help you."

According to an urban participant, "...it is a question of the current economic hardships, hence they themselves will not be having any," (Urban p. # 7-10). She gave the example of her own relatives, not her husband's.

*Like those on my side, you can actually see that they care for me, but they have nothing, because they are always coming [to visit]. They never skip two days before they come around. They come to see how we are doing, what is happening, (p. # 7-10).*

Another urban participant that passed comments about his close friends and neighbours said:

*Most times what they can afford doing is coming to check if I haven't met with any problem, check how I have slept, spent the day, how the children are....These are the things they can afford to do, (Urban p. # (9-8).*

However, for most participants, it was through those visits that emotional support was provided. For this participant, these friends that came checking out how he was doing with his children, including the sick one, was a show of moral support.

Therefore, when participants answered questions regarding what supports their network members brought them, or how their relatives or friends were supportive, the following responses were typical:

*No, they don't, they just come ('kwete, kungouya chete'), "How has the child slept? How is the one at the hospital," just that. Not that they come with anything, "(Urban p. # 4-5).*

*Aaa, nothing, just words of encouragement, helpful words, (Urban p. # 5-6).*

*With words [of encouragement and comfort] only ('nemashoko chete'), (Urban p. # 15-5).*

The comments made by this female urban participant serve as a good summary on the reasons why network members were currently less supportive. The comments were also quite insightful, because this is the perspective from the caregiver's worldview, something different from reasons centred on social reactions to AIDS/PWHA.

*The main problem that I see is that money is hard to come by. Because if we look at a family today, one hardly gets enough to support her wife and children. And for someone to find anything to take away so they can support someone else is the biggest problem I think. Because things like*



*rent, electricity and water are also affecting them. And they also need food, you see, and one can hardly spare anything to spend on relatives. I think that is the biggest problem, (Urban p. # 12-2).<sup>15</sup>*

Participants reported many different types of emotional support, but the most frequently mentioned was the act of moral support embodied in particular greetings of the day, (e.g. how has the patient spent the night? How are you doing together with the patient?), followed by words of comfort and encouragement. An example of words of encouragement are, "If you lose heart, nothing positive will come out of this," (Urban p. # 1-7). Some "...come around to comfort..." saying "...take heart, that is how life is, putting your mind at ease..." (Urban p. # 10-1). Another urban participant gave quite an interesting example of one of her two friends that would come and raise her morale whenever she found her depressed, while in the company of the patient. This was the friend she said made her feel she was well supported.

*[S]ometimes when she came into the house and there was total silence, she would call me aside and tell me, "A! a! a! a! What you are doing ('zvamaakuitaka izvo') is not good. This patient is very conscious of what is happening. Don't do that. What do you want her to think if you remain quiet like that?" And she would start talking stories, and we would laugh and all, and she would end up by saying, "Let us pray", (Urban p. # 11-1).*

With some participants, however, you could feel the sense that these 'empty hands visits' to offer solidarity or moral support did not mean much to them. Which again reinforces my earlier assertion that the prevailing economic hardships had conditioned people to expect material supports, just so they could pass from one day to the next. A good example is the response to a question on: 'There are times when we need someone to understand what we are going through, especially concerning caregiving. How many times did you see someone listening to your problems, or what you think?'

*I can't say how many, because the people come at different intervals. Yes, the people show concern, and that they are troubled, but for them to give enough support now is the problem, because when someone is troubled you feel the need to help. But it is the help that is lacking, they are failing to help. They have a lot of pity and anguish, because of the way things are going, but ah...[speechless], (Urban p. 12-1).*

Another urban participant that shared this view responded to a question on whether her neighbours were supportive whenever she encountered any problems by saying, "...they



are not supportive. The only help they give are words of comfort," (p. # 5-6). A rural participant also talked about 'empty hands visits' in a way that signified that these were not really relatives in the fullest sense, and she indicated that these were now in the majority.

*They are in the majority, those that are relatives by name only (ndidzo dzikawanda dzepamuromo'). They can come to visit, but they never come with anything in their hand for the patient, (Rural p. # 3-1).*

However, there were other participants that voiced appreciation of such support, regardless of the absence of material help.

*[T]here is my husband's nephew who is unemployed, but he used to come and support me with words of comfort as well. You would realize that he understood what I was going through, but there was nothing else he could do [monetary wise]. But that was his way of helping, (Urban p. # 13-3).*

Another participant said this when asked the kinds of helpful supports she got from her relatives:

*[M]ostly moral support, they are very helpful. They come here very often, even without money, (Urban p. # 2-3).*

Overall, participants that had members of their church in their network received relatively more emotional support. As stated earlier, more participants received more emotional support than instrumental support.

Informational Support: - Participants reported receiving informational support from members of their network mainly in the form of ideas on how to tackle everyday problems, or advice. Advice was offered in a variety of contexts, including: food that patients should be fed with, going for TB tests, use of gloves when washing the patient's clothes of bathing the patient(s), and how to try out other medical systems (e.g. traditional medicine). Most of the informational support given to participants was from persons that had similar experiences, and I will talk about this below under 'Peer support'.

Some friends or relatives gave advice "...such as trying out traditional healers to complement Western medicine..." or "...to consult with spirit mediums so that they explain the cause of the disease..." (Urban p. # 12-2). Some get advice to try out spiritual healers ('prophets') (Rural p. # 2-1M).

All participants that had spouses considered them a good source of informational support in the form of advice. Also, just like emotional support, most patients felt that



some (if not most) of their network members offered more informational support than instrumental support.

*That neighbour of mine helps with advice. She is the one that usually manages to come by and talk, as well as to check on the patients in the mornings...That is what she can afford, (Urban p. # 10-1).*

Affirmational Support: - There were only two references made to affirmational support. The first example comes from a participant that talked about her uncle that she said had come two days before, saying to her, "This requires dedication my child..." (Rural p. # 1-1). After seeing what his niece was going through, he realised the difficulties she was facing really needed commitment. He was therefore paying her a complement to spur her on. The other example is that of another rural participant that talked about her husband's sisters whom she said paid her complements that indicated to her that she was doing an important and difficult job, and that she should not lose heart.

*It is a burden, because it is not easy, because it is not easy to say, 'I have a patient, I go into the field, and I have to cook for school children.' It is difficult. You hear other people such as those I call sisters-in-law saying, "Aaah, you are actually putting us to shame by the amount of work you are having to do here. How are you managing?" ... (Rural p. # 4-1).*

### Peer Support and Social Comparison

Much of the informational and emotional support provided by network members came from persons that were currently looking after a patient, or had also looked after someone with a similar disease, be it TB or AIDS, depending on what the caregiver chose to tell the person providing the support. More urban than rural participants reported receiving emotional and informational support from members of their social networks that had experience looking after PWHA.

Some participants had received support from more than one person with a similar experience, and the majority of caregivers had received such support. This kind of support created confidence in caregivers. The confidence arose from the transfer of knowledge as well as from knowing that they were not alone in this fight against AIDS and the attendant stigmatisation and discrimination. Confidence also arose from knowing that if these people could, or can do it, so can I.



One participant who talked about a woman that had once looked after her husband's sister that told her that, "These people [PWHA] can survive much longer..." with good care. She went ahead to say.

*So, she has the knowledge that one needs fortitude, because one is likely to meet many obstacles. And as for me, exactly what I was told by that woman came true with my sister. Therefore, you could see that she had looked for a patient, for real, (Urban p. # 11-1).*

Apart from this woman she spoke of, there were many others that also came to support give her emotional and informational support in terms of what to expect:

*They used to come, many of them. They all used to help me strengthen my resolve. Saying, "We have also seen people like this," and one would say, "I once went to the rural areas and saw my mother looking after my aunt," "I saw my mother looking after my sister, it is difficult but it's very possible to accept it," (Urban p. # 11-1).*

Another urban participant also indicated that she had received such support from five different people that had undergone similar caregiving experiences.

*Right now there are many of them....They are coming to have a look [at the patient], and most of them just say things like, "my sister was once as sick as this, and she ended up like this, and these sores....so you have to be strong and keep bathing her." And one says, "I looked after and washed three different people, a sister-in-law, mother-in-law," and now she has a sister whose illness is similar to this one, and they are also engaged in similar duties of washing the patient. You see. Most people are just telling me that I need to be patient, and that [she] needs to be washed at least twice a day, (Urban p. # 12.2).*

An urban participant that had received emotional and informational support from a friend said that she had learnt a lot from the encounter, because "...it shows that she has first hand knowledge, since she lived with someone with TB as well, and it gave me courage, such that most times if she behaves like that I just talk to her patiently..." (Urban p. # 14-4).

### Nature of Support

Supports from formal organisations were unsolicited for the most part. Because the supports would be normally intended to be for PWHA or caregivers, the only thing participants had to do was to request for something that they needed, knowing that they were entitled to receive the supports. There was a slight indication that more of the



supports that participants received from network members were solicited. In other words, caregivers had to more often than not, ask for assistance. The source of the support (i.e. friend, kin, neighbour), did not seem to have any bearing on the nature of support, that is, whether support was solicited or unsolicited. However, this only applied to instrumental and informational supports.

*Solicited Support:* - With some participants, to solicit or not to, depended on a number of things. For some it depended on the network members that might only choose to give when asked for support. For one participant, it "...depend[ed] on the state of mind neighbours..." found her in when they visit, (Rural p. # 1-1). When she felt like it, she would ask for items such as "...paraffin, matches, salt, or money for the grinding mill, " (p. # 1-1). Another participant that sometimes did not ask, said he sometimes asked because he realised that if he did not do anything about the situation nothing would improve. He also had to solicit for support from his sister because she might think "...since he has not told me or other friends of his, he must be okay..." (Urban p. # 15-5). One urban participant that said she normally did her own things, and did "...not usually ask for support," also said that on occasions she had to ask for support, (Urban p. # 2-3).

Participants that were not iffy about soliciting for support indicated that they would solicit for support "...whenever there [was] an illness or something had happened," (Urban p. # 14-4). One participant talked of having to plead to her neighbours sometimes, in order to get some corn meal to cook for her brother. She said to get support she "...would have gone to [ask the neighbours her]self...most times..." (Urban p. # 3-4).

Another participant talked of having to borrow from neighbours, not just asking for help.

*When I am really desperate I can borrow some corn meal and give them back when I buy some... You have to ask for it. And thereafter they will be asking you, "Haven't you bought my corn meal yet?" [Laughs] Yes, some do not care. They say, "Someone else's problems?" ... (Urban p. # 6-12).*

Other relatives waited for someone to have to ask for support, and one rural participant talked about a neighbour that they had to send a child to call every time they had a problem.



*[E]ven if they hear that she [daughter] is sick, they don't come. But if you are very disturbed at that time, you might just have to send someone to ask them to come over, (Rural p. # 7-1).*

This participant also indicated she would have a relatively good comfort level solicit for small items such as salt from neighbours.

*Unsolicited Support:* - Some participants did not normally solicit support because members of their network quickly read their situation and offered support. When I asked one participant how she knew her friend cared about her she said:

*When she comes here she asks, "Do you have food here? If you do not have any, come with me and collect some vegetables..." (Rural p. # 5-1).*

Another rural participant said of her friend, "If it is this one, I don't have to ask, she just knows that I need support," (Rural p. # 7-1). Two urban participants that received a steady supply of support, one from a cousin, and the other from brothers and sisters gave a similar response.

*Most of the time if it is she, I do not have to ask for support. She just gives. We might not even have talked about the existence of a problem, (Urban p. # 10-1).*

*No, sometimes they buy things before they come here. Or they come and then ask me what is needed, (Urban p. # 11-1).*

In these cases and similar ones, participants had network members that understood their position and offered support without requiring any solicitation.

There was one participant that said she did not solicit support because of consideration of the other person's circumstances. She did not solicit support from two of her friends because one of them was "...also a[n AIDS] patient herself," and the other one's husband was unemployed," Rural p. # 1-1).

*Long-term and Short-term Support:* - There was no indication of the existence of any long-term support for caregivers from any organisation, government or non-governmental. The only support that came close to long-term was the scheme started by Mashambanzou to enable PWHA to start income generating projects. However, these do not have a direct benefit to caregivers. Most supports flowing from network members and organisations had therefore, short-term benefits. There were only two examples of long-term support from network members, all given by one urban participant.



The first one is a kind of a burial society, whereby people that lived on adjacent streets made an agreement to support each other by making contributions whenever a member lost a close relative. This kind of support system is long-term, firstly, in the sense that it was there and available for any of the members to make use of, in the present and in the future. It was also long-term in the sense that one could use it again in the future if another family member was lost. The participant had utilised this support many times before, when close relatives had their funerals conducted in her home, and she used it again after her AIDS patient died. Each member (i.e. everyone that lived on that street and the one behind it) contributed ZW\$15 each time there was a funeral. Although the participant could not recall how many households were involved, she said the contributions usually came to about ZW\$300 or ZW\$400. This is not a specific figure for specific households because at times "...one can say they do not have that but can afford ZW\$10.

*Moreover, on this street, we made an agreement that whenever each one has a funeral at their home, each one contributes a certain sum of money, and corn meal. To come up with that we would have sat down, the women that live on this street, then look at the things that are needed most at a gathering. Then we realise that food is the item that causes most problems. Therefore we... contribute corn meal and money to [help] whoever has been affected... (Urban p. 11-1).*

The second example of long-term support is that of an arrangement, in the form of a mutual aid society organised by this participant with five of her friends living on the same street, and had been in operation for "many years...". Each one contributed ZW\$500 per month towards this cause, which they raise from the initial contribution of ZW\$100 per person. These contributions also went towards buying groceries (e.g. cooking oil, sugar).

*We do have a form of mutual aid society, [a.k.a. 'rounds]' ('tinotamba ma society edu, emidziyo'), whereby we give each other utensils. So, we meet at the house of the person whose turn it is to receive the utensils. It's just like a mini party, then we give each other whatever we have brought and that's it. That is a good time for us, because we also pray while we are in that gathering....So, that is how we are able to support ourselves. We get ourselves utensils, and every woman needs utensils.... Like myself, for me to buy proper things I use the money from the rounds ('fanika ini kutenga zvinhu chaizvo kutotenga nemari ye round'), (Urban p. # 11-1).*



## Social networks and social support

There were six participants with social networks comprising four or less members in the urban sub sample, compared to two in the rural sub sample. Two of the urban participants with two and three network members respectively, were of Malawian origin, with few relatives in Zimbabwe. This supports the finding in this study that kin played a strong role in providing support to caregivers. Most networks, as shown in Figure 3, were comprised mostly of kin, a few neighbours and friends.

The most significant finding is also the fact that most participants included people they went to church with, or members of their mutual aid groups, who tended to be their friends, as belonging to their network. Although most members of each one's network knew each other, since they tended to be mostly kin, there tended to be a few members that did not know each other intimately. These tended to be acquaintances from church or other support groups/

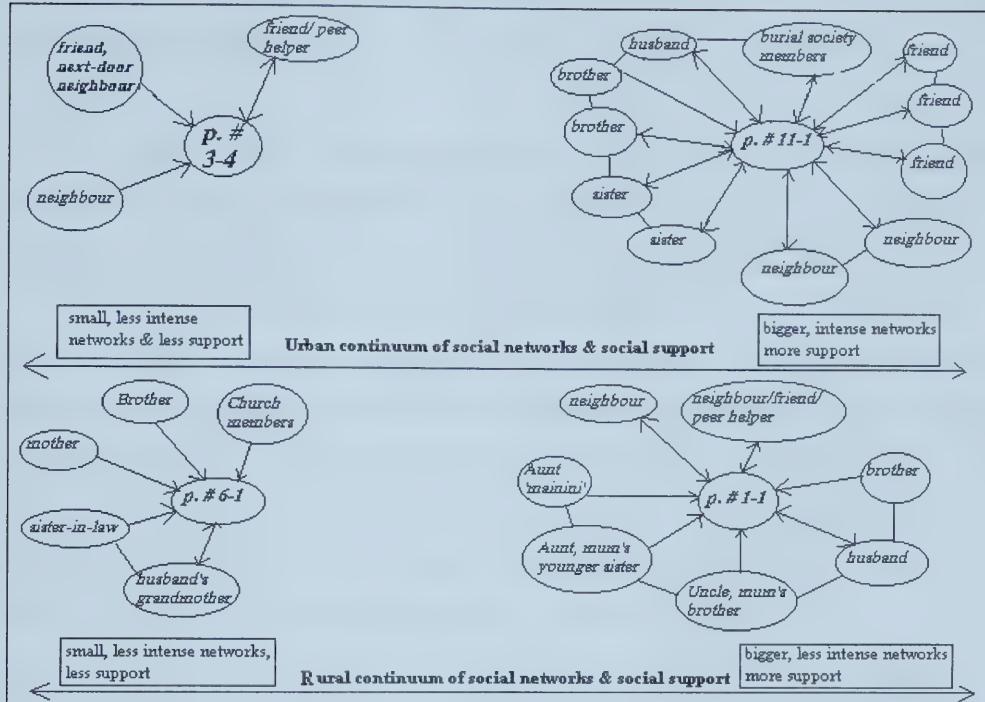
There was no difference in network size and support received between male and female participants. There was also no difference in network size between the urban and rural sub sample. Also, network size did not always translate into material support received. For example, the two female participants (i.e. 11-1 and 2-3) that reported being relatively content with the material and other supports they were receiving from network members had about seven members in their circle, while another male participant (15-5) that reported eight members received very little material and moderate emotional support. These two female caregivers are the only ones that also had networks that had high-intensity relationships and long-standing intimate social ties. These two participants seemed to have connections that had a socio-economic status above working class level.

Most of the other participants' social network tended to be more diffuse, and composed of less intense ties. The majority of networks were characterised by lack of reciprocity from the caregivers, particularly with material support.

Figure 3 shows two continuums of urban and rural social networks. Each continuum shows the participants with the least number of network members and least received supports, and participants with the most number of network members and most received supports.



Figure 3: Comparison of Social Networks



In the case of all participants, there were more support flows from other network members than from the caregivers, particularly material support, mainly due to the illness in the home, as well as their state of deprivation. In the four examples in Figure 3 on the next page, only participant 11-1, had a denser, and more supportive network with more members that knew each other. Participants reported more informational and emotional support flows than instrumental support.

#### How does it feel to be supported?

The feelings that participants had about support from either formal or informal sources were as varied as the number of individuals. How participants felt also depended on the perceived adequacy of the supports, as well as their timeliness. Generally, however, most participants that received the supports they needed felt 'thankful' and 'loved'. Some also felt their hearts 'settle down', that is, they felt relieved. In this section I



am going to deal with issues or personal experiences pertaining to the right side of the Venn diagram in *Figure 2*.

*Formal Supports:* - The inadequacy of formal support services resulted in fewer comments about how participants felt about support emanating from this source. But the few that received appropriate supports when they needed them felt thankful.

An urban participant that had received what she believed her patient was receiving excellent care at a local private hospital, compared to the government hospital she had previously taken her, felt the hospital personnel had '*concern*' for their patients, and was '*thankful*'. She also felt the Red Cross HBWS that had assisted her with supplies, a referral for the patient's son to go for an X-ray, and had come to pray with her had given her good support, and was touched by their concern. She therefore went to the health centre to thank them when the nephew eventually stopped coughing.

*Yes they were supportive enough, because buying Betadine...Jik...even the gloves themselves...[and] cotton requires money. These are things that I used time and time again, so, if I did not get help from them I was going to have to keep money at hand for purchasing these things. And I would like to thank them for the way they supported me, (Urban p. 11-1).*

However, due to the sporadic nature of supports from the Red Cross, there were no similar widespread feelings of thankfulness for their services from participants.

Most participants that were supported by Mashambanzou also felt thankful for the supports that were provided, especially when they were received during critical periods of food shortages, or when one needed urgent support with other illness-related supports. Here is a good example where a participant felt Mashambanzou people showed concern for their welfare, because they brought them back from the brink of starvation.

*Those from Mashambanzou show a lot of concern, because they try all they can to put things right. Let's say, for instance, you have nothing, to the extent of sleeping without eating anything, and there is nothing even for tomorrow. Maybe you are at a stage where you are eating vegetables cooked without any cooking oil, and yet the patient needs to eat nutritious food. And they come and give you food, they give you cooking oil and beans, which is nutritious. These are the only people that show some concern with our welfare... (Urban p. # 7-10).*

The following is another good example of a participant that felt *relief* after one particular support episode, and was *thankful*. After the initial contact between the



outreach nurse and the participant, during which the former provided emotional support, material support was provided on a subsequent visit. The food items were supplied in my presence, therefore, the reaction that I observed on that day, and the participant's description of how she felt, a couple of weeks later, presented to me a complete picture of genuineness in appreciation of these supports. Commenting on the material support, the participant said:

*That was very helpful...we did not have even a grain of corn meal...that day...Even cooking oil, we had just a little bit, so they helped us quite a lot, (Urban p. 11-1).*

And this is what she felt about provided emotional support:

*Uhhh, that woman comforted me very much....She really consoled me a lot....[S]he helped me gain control of myself, I had reached the end of my wits. A lot of thoughts were running around in my head, concerning his illness....but she said, "No, people can just get sick anytime.".... Isn't it that day she gave us tablets [i.e. painkillers]. Even this one [i.e. neighbour] talked to him [patient] after the nurse had gone, and he said that he also felt comforted a great deal. Aaah, that woman is very good... she is very nice that woman, (Urban p. # 2-3).*

Another participant that was thankful for the support she was getting from Mashambanzou indicated that although it was not enough to meet her needs and those of her two patients. According to this participant, "...whenever you receive something, you say 'Thank you' [clapping hands]."

*We can only appreciate that we are being supported. We cannot belittle that support. Whatever they give you, you cannot belittle it, because you would have been helped... (Urban p. 4-5).*

Among the rural participants, those that expressed their feeling about support provided did so in relation to supports from either Motoko Hospital or their religious denominations. One participant whose son received free health services for TB treatments said this was "...helpful, because it would have been a burden..." if she had to pay for the hospital fees, (Rural p. # 4-1). Another participant indicated that she was *thankful* for the emotional support she received from the hospital personnel.

*[T]hey comforted me a great deal, because by then I didn't know what else to do, (Rural p. # 6-1).*

Those that talked about the supports they received from their church made comments largely about emotional support. This is one good example:



*My heart feels settled, because I feel that I have got a comforter. [My heart sure feels elated, I feel cooling effect ('kutonzwa kutotonhorerwa', or feeling as if I have no patient, or that there is nothing troubling me...because they would have consoled me...I can say those from church are the ones that console me the most, (Rural p. # 7-1). [My emphasis]*

One other participant talked about how she felt regarding both material and emotional support. She first of all talked about the contributions done at her church ['chita'], whereby "...people contribute, be it a dollar each or...and they put the money together...and they come and give you" (Rural p. # 3-1). The last time this was done she had received ZW\$40. When I asked her if this was helpful, she said, "I can say it is helpful...I feel happy and peaceful ('ndotonzwa kufara, kusununguka'), (Rural p. # 3-1).

Referring to the emotional support she received, she also said, "

*It is helpful because I hear many words [of reassurance]. They tell me, "Don't worry...[her name] these are common things these days." And if I had been feeling low, or my blood pressure was about to go up, it goes down because I am seeing how I am being consoled with these words of comfort, (p. # 3-1).*

Informal Supports: - Most participants talked about feeling '*loved*' by supportive relatives, friends or neighbours. Some felt *relieved*, while some felt *thankful* and *pleased*. Most participants that were appreciative of the little support they were getting from their network members took the approach that they should not belittle whatever they received.

*Aaa, you just say to yourself 'half a loaf is better than nothing, (Rural p. 1-1).*

*You cannot look a gift horse in the mouth, because whoever helps you out is showing you s/he is someone close to you, (Urban 13-3).*

Some participants felt cared for loved by their supportive network members, and were therefore thankful. For example, one urban participant whose husband had suggested they take in her sister and look after her in their home said:

*God blessed me with the desire to help others. So he came through the man that married me. I don't know how I can ever thank my husband...My husband cares a lot...You can see that he really means what he says. Therefore, I thank my husband very much, because there are others who forbid their wives to bring their relatives into their homes, (Urban p. # 11-1).*



This participant also felt greatly loved by her two ever-supportive friends. She said the following about these friends:

*[I]n happy times, during problems, they are always with me. Therefore, I know that they just don't love me so when can enjoy life, they love me even when things are tough going... (p. # 11-1).*

Another urban participant that received emotional and informational support (in the form of 'ideas') from her niece (sister's child), whom she described as the only person that came to her assistance during the illness of her two children, said that she felt loved.

*I just thought she had a lot of love, that such a young person would come to say that to an adult person like myself. (Urban p. # 5-6).*

Other participants felt 'pleased' (Rural p. # 2-1M) and 'relieved' at receiving supports from network members. Emotional support was also felt to be 'comforting' (rural p. # 4-1) as well as "help[ing to] loosen up the inside of [one's] heart...('anondibatsira mukusunungura mukati memwoyo wangu')," (Rural p. # 4-1). This same participant also talked about being *thankful* that someone would come and see her patient. *Happiness* is what other participants felt at receiving support from friends.

*I am quite happy that they [i.e. friends] have come to see me. My heart goes like, "Oh, they have remembered me today," (Urban p. # 4-5).*

Others felt that support group members cared about them, "...because we are facing the same problem, and therefore understand each other," (Urban p. # 7-10). One participant made a comment about relatives from her family that came often to visit, which gave me the impression that she felt more connected to these relatives. She said, "Yes, they are the ones that come often, those are the people I can call my relatives..." (Rural p. # 6-1).

*Adequacy of Support:* - None of the participants ever mentioned that they were getting adequate support from any of the organisations discussed above, except the participant that had a sister in a private hospital. This is the same participant that also indicated that she was getting a lot of support from her friends and siblings. However, when I asked her if the support she was getting was enough for her, she said:

*It might not be enough, but I have somewhere to start. Knowing that it's a new day, and since it's a new day, I now have to do this and that for things to work. [Y]ou cannot expect to get all the things that please you from someone who has their own family. No one is oblivious of the prevailing difficult economic situation that faces us. So, you have to*



*learn to be content with whatever someone gives you, because they are having to support me here, and their home as well, (Urban p. # 11-1).*

The majority of participants indicated that either the supports they were getting from network members were enough 'given the provider's circumstances', or considering that one cannot belittle what one has been given. Otherwise, supports were largely deemed inadequate to meet caregivers' and patients' needs.

The following were some of the representative comments about the support participants were receiving from Mashambanzou:

*Those [supports] from Mashambanzou are not enough, (Urban p. # 10-1).*

*It's a good thing they are doing, but by the end of the month there will be nothing left. Like right now there is nothing [i.e. food] in this house.... [later] No, it's not enough, not enough, not enough, not enough, (Urban p. # 1-7).*

*At the moment it is sort of helpful, but this is not sustainable, because after a while I run short of these things again, (Urban p. # 9-8).*

*They do their things hurriedly in order to see everyone, (Urban p. # 7-10).*

Earlier on I indicated that most of the participants in the suburbs services by the Red Cross Society did not have a clue about their support services. However, one participant made the following comment, which is indicative of the inadequacy of their support for caregivers.

*There is not much support coming from the clinic. The home-based care workers only come maybe once a week, to check how the patient is doing. Sometimes they give us some gloves or Jik, but now it has been a long time since they did that, and the ones we are using right now we bought for ourselves, you see, (Urban p. # 12-2).*

By virtue of the fact that each of the participants cited numerous network members that were not supportive, as well as the fact that the caregiver's needs as well as their patients' were quite considerable, supports from this source were largely deemed inadequate. The following are some of the responses made by urban participants about supports from network members:

*No, it's not enough, it's not enough....they give it to you in a plate, and that could be corn meal, it could be salt. Only. Not the type of help involving big things? (Urban p. # 15-5).*

*Not a single bit, I wouldn't want to lie to you, never, (Urban p. # 3-4).*



*It is not enough. They cannot possibly satisfy our needs. That is why I use my hands to try to make some income, (Urban p. # 6-12).*

*No, it's not enough for me...they do very few things for me, and most of my needs are not met....most of them just give you maybe 50 cents to buy some salt, (Urban p. # 9-8).*

Rural participants made some of the following cut and dried comments about the adequacy of the support they received from network members:

*Aaa, it's not enough, not enough, (Rural p. # 4-1).*

*It is not adequate, (Rural p. # 5-1).*

*It's not enough, (Rural p. # 6-1).*

*No, not even a single bit, (Rural p. # 7-1).*

Overall, participants painted a picture of largely unmet support, either for their benefit or for the benefit of their patients. Given this picture deficient in contour of support flows, it is therefore pertinent to explore how the participants actually feel about it

#### How does it feel not to be supported?

Earlier on I touched a little bit on how participants felt about unreciprocated support, amidst a culture that imposes expectations that sanction reciprocity. The issues here on how one feels about not being supported adds to that discussion. Lack of support resulted in many negative feelings developing in caregivers. For one, lack of support confirms suspicions that society shuns PWHA and their caregivers. Lack of support, therefore, makes caregivers feel *worthless, neglected, and disappointed*.

Among those that revealed their feelings regarding lack of support from organisations were two urban participants. One of them took her bedridden sister to the nearby clinic where it took more than one and a half hours before the patient received her daily injection, all the while lying on a bench, mourning.

*There was only one nurse that was taking information from patients, as well as giving injections. The rest had gone for tea. We asked her to help us quickly since we had an emergency... The patient was beginning to complain that sleeping on the bench was becoming painful for her. She was already crying with pain then, since she has sores all over her body, you see... So we told the nurse that and she goes, "My legs are now sore. I cannot do injections and then come back to take patient information. I have to do this first... I have already noticed your presence, and I am*



*coming." We tried to plead with her and she then said, "...If you insist I will stop all this and go for tea as well." ...Then we went back to the bench, and our patient then ...wanted to visit the toilet...She only managed to kneel down by the bench and passed urine, then I put a blanket for her to sleep on the floor instead, because the bench was too painful for her, (Urban p. # 12-2).*

When I arrived for my first interview with this participant, I had to wait a few minutes before they arrived from the clinic where they experienced this ordeal. She said that she felt *irked* by this kind of treatment, as well as *ignored*. Another urban participant talked about her experiences with the local government hospital where she had taken her patient a number of times before. She also felt that her patient was being ignored by the health personnel, who failed to change the patient's clothes and linen regularly, such that each time they visited they would "...see urine coming right up to the back of the patient's head...sleeping on wet linen, (Urban p. # 11-1). She also felt that they were shunning her sister.

This experience, in comparison with her new experience at the local private hospital where they had recently taken the patient to, made her feel that '...poverty is bad'. This is because poor people cannot afford to send their loved ones to the private hospital where there was better care, and ended up going to the government hospital, with dire consequences.

*So you just see that there is a very big difference, such that if you are poor you die... just like that, and if you have money you will get better treatment, (Urban p. # 11-1).*

In essence, the participant was speaking to the issue of felt marginalisation by the system that operated in favour of the rich.

Some participants that talked about lack of support from network members mentioned feeling '*worried*', and '*upset*' by the absence of support. To some the experience was *painful*. A participant that went to Harare for a medical review and hoped to sleep over at her brother's house before coming back to her rural home, had her feelings hurt by the brother's '*diplomatic*' refusal. She said that this experience was *disappointing* to her.

*It really disappointed me....I thought maybe he thought I have a disease, and if I came over and used his towels and other things, things wouldn't go well after I left, (Rural p. # 7-1).*



However, a few other participants did not display their feelings on their sleeves, and decided to play down the effect of lack of support. One said that it "doesn't matter" (Urban p. # 5-6), and the other said she felt 'nothing' because the other person 'doesn't have', (Rural p. # 4-1). One other participant showed her Good Samaritan side:

*That happens, but you just have to understand that that is human nature....If you have a soft heart, a religious heart, you do not dwell on that. You just ignore them and keep on supporting them, that will make them shy and tomorrow you will see them doing what you are doing, (Urban p. # 13-3).*

There are not many options for someone who is not receiving support from network members. Either you stay put, or you go ahead and ask for it.

### How does it feel to ask for support?

Some of the issues pertaining support seeking were indirectly addressed in the section on 'solicited and unsolicited support'. When support is not forthcoming from one's network, the onus falls on an individual with regard to what to do about the situation. Most participants showed reservations about seeking support from network members. However, a few indicated that they had no problem going out soliciting for support, but this depended on the person whom they were going to seek it from. For most participants, seeking out support from network members that they also supported was not a major problem. For one rural participant that reciprocated support with a friend, asking for the friend's support "...is very easy for..." her, (Rural p. # 5-1). Similarly, another rural participant indicated that she felt '*quite free*' to ask for support from her friend whenever she encountered a problem. Here is her reason for feeling that way:

*Because she also free to talk to me about whatever she feels, or giving me things without having asked for them, (Rural p. # 6-1).*

Another rural participant said that she "...feel relieved" because she at least has someone she can "...go to ask for help in times of need," (Rural p. # 2-1F).

For most of the participants, asking for support was felt to be a *shameful* and *difficult* thing to do.

*The problem with relatives is that, you try to refrain from asking [for help] because one might not want to help. And even you yourself, you end up being ashamed of yourself, from repeatedly going to ask for help, (Rural p. # 8-1).*



*Asking for support is difficult for me most of the time, unless someone just volunteers...I cannot ask for more, (Urban p. # 10-1).*

For others, soliciting support:

*[I]s difficult...because some people don't know how to talk ('zvinondinetsa nokuti kutaura vamwe havagone'), you see. Some will say to you, especially when they are drunk, 'ahh, you have nothing you, we are the ones that helped you' ('aah, munechiwo chamunacho imi? Eeh, ndisu takakubatsirai'). So, that is what I [try to avoid] ... (Urban p. # 15-5).*

Therefore, for this participant, soliciting for support brings with it shame. This is particularly more so in a culture where men are supposed to be breadwinners. Soliciting for support and later hearing such kind of talk would make one feel belittled, especially for this participant that had since lost his job as a cook. For this participant, asking for support also made him feel as if he was *troubling* his relatives and neighbours.

*I cannot ask them, 'hey you, why don't you help me?... It's not proper ('hazviite'). You just look at them, you just look at them. With time they will realise they should, that there is this and that lacking... They will realise on their own.... I feel as if I am troubling someone, (Urban p. # 15-5). [My emphasis]*

Some participants that feel soliciting will lead to the termination of their relationship with the would-be support provider also consider it problematic. According to one urban participant:

*Asking is a bit problematic because...some people will never come back. They begin to think that each time they visit they will be asked for support. "They are a nuisance, they will ask for stuff, so we are not going there anymore." [Laughs] So, it's better for one to give from their free will, (p. # 10-7).*

This participant also had the same concerns as participant 15-1 above; that people would *gossip* about her and her family, and this would bring feeling of *shame*. According to her, it would be better just telling her other relatives just that she is sick, but not to tell them what she is lacking in her home.

*Actually, they might even go around in our rural area laughing about our situation, so just realise that keeping quiet is better...I once heard that they went back to our rural area saying, "They are leading a hand-to-mouth existence ('varikutambura'). They are living on welfare," just being derogatory... (Urban p. # 10-7).*



It has therefore emerged that seeking support is not as straightforward as it might seem. Each and every caregiver has a number of personal considerations to make, and the common one of is just to wait and see what comes their way. There are also some supports that come their way, whether well meant or not well meant, and they see them as unhelpful.

### How does it feel to get unhelpful support?

There were a number of supports that were considered by participants to be unhelpful. Some of these were from formal and some from informal sources. There were also various reasons why supports were considered unhelpful, depending on the nature of the support versus the need, as well as one's interpretation of the intent and benefit to them

Formal: - There were a number of formal supports or aspects thereof that were considered unhelpful by participants. For example, the reintroduction of user fees into the health system has had negative effects on services utilisation. This means when participants take their patients to a health centre or hospital for any other opportunistic disease (other than TB which is treated free of charge), they would have to pay. Hence one participant said that their local clinic was no longer helpful, "...because we pay for service," (Urban p. # 1-7). Moreover:

*[T]hey can help me if I present with a cough or other things, and then I pay... but with such diseases as these ones [i.e. AIDS] they do not help in any way. What I have observed is that clinics are not there to help people any more. They just want people to die in their homes, (Urban p. # 1-7).*

This was a sentiment shared by most participants that felt that sending patients back to their homes to receive home-based care was burdening them instead. A related aspect of unhelpful support concerns the issue raised by another urban participant that witnessed a withdrawal of full support for her hospitalised sister. In this government hospital, where the patient was supposed to be getting help, "...they were even afraid to give her more blood, because she had this particular disease...and they were now seeing her as someone



not deserving help," (Urban p. # 11-1). Also "...you could go there and get told that she [patient] had messed herself up four times, and they haven't changed her," (p. # 11-1).

This is unhelpful support, because a patient is admitted into the on the understanding that s/he is going to get help. This participant also considered this particular hospital as providing unhelpful support to her because, on the day of discharge, they would not give her basic things such as gloves and disinfectants to go and use on the patient at home.

*[W]henever they admitted her they used the essentials on her themselves, and when they discharged her, they would not give me anything. I would just come home empty handed, (p. # 11-1).*

A rural participant also considered lack of empathy on the part of health personnel that attended to her son as unhelpful support.

*They just regard it as part of the job at their workplace. They treat many people, and they have nothing to do with him, (Rural p. # 4-1).*

Mashambanzou outreach personnel work under immense pressure, in terms of the number of caregivers they have to visit. As a result, the quality of the outreach work is compromised. This hurried nature of their services was a cause of concern to one participant with three patients. To her this was unhelpful support because support they were providing did not seem complete.

*They just come, 'How have you slept patient' ('warara sei murwere')... What is the problem today?' 'I am coughing.' And they go to the car to pour some medicine for him or her, 'Keep taking that medication' ('wopota uchinwa mushonga'). If they happen to be tablets, 'Take these tablets and take them regularly.' And that is all, (Urban p. 10-1).*

Besides giving one a sense of not being valued, such hurried interactions could also be construed by a person a feeling of being shunned, as might have been the case here. The same participant also raised the issue of raised expectations, which she regarded as unhelpful support. After an outreach nurse from Mashambanzou promised to help her with arrangements of hospitalising one of her three patients, nothing materialised from that arrangement.

*There was a time when I told them the patient was getting seriously sick, and I wanted the patient to be taken to the hospital. They just came and told me that a bed would be booked for him. After they said that they never came back. They did not come back again, until I called for an ambulance on my own, (Urban p. # 10-1).*



This account gives us the sense that the participant felt let down.

Informal: - Participants reported more instances of unhelpful support from interactions with members of their social networks than those from formal organisations. In an earlier section I talked about participants that did not feel like having received any support if it did not include material things. According to those participants' point of view, it is unhelpful for one to come and give only emotional support without giving them something tangible. I have also discussed earlier, the issue of visitors that come to see the patient, pretending to be sympathetic, and then later on go around spreading rumours about the disease they thought the patient was suffering from, as well as other things. This is also as aspect of unhelpful support, from the perspective of caregivers.

At times relatives and friends come to visit the patient and offer informational support. To some caregivers, some forms of advice consist of unhelpful support. For example, one young male participant described how suggestions to seek help from another medical system were unhelpful.

*She is the one that comes by and suggests what we could do with the patient. She is an old person, and old people want to go to traditional healers. And I tell her we are not going, that all those things [traditional medicine] do not work, it's a waste of the little money hat we have. We should be looking for means and ways to buy adequate food for the patient, (Urban p. # 1-7).*

In this case, this young man felt that the grandmother was taking them back into the Stone Age, and that her suggestions would lead to a waste of resources.

Other participants felt let down by relatives or friends that suggested a course of action, but then failed to provide support related to that suggestion. When I asked one rural participant to give me an example of unhelpful support, she cited an incident when her uncle asked them to prepare and get ready to go to the hospital with the patient.

*After we had gotten ready, aunt asked, "Where is the money?" and he said, "I am only there to guide you on how to do these things. You are the ones with a brother that is working, so you look for the money." So we never went, because the money wasn't there, (Rural p. # 5-1).*

Many other participants cited this kind of unhelpful support, but an interesting example is that of a participant that talked of neighbours that suggested she take her daughter to the hospital, but failed to support her with any resources to put this into effect. The



interesting part is that those although those neighbours might not have had monetary resources, they had other means they could have helped.

*There is nothing they help you with. Yet someone might be having cattle, but they never think of harnessing those cattle so they can take her to the hospital. If you ask, "How about your cattle?" They are quick to say, Ah! My cow is not well these days." Or, "My scotchcart's wheel has a puncture,"* (Rural p. # 7-1).

She went on to state that these people would be giving all that advice in order to be seen as consoling her. Another participant that received advice that he thought was unhelpful talked of how people raised his hopes but failed to put any of their words into action.

*It's like, they can give me advice, such as, "If you could do this, we might add on to that with this idea." Which means they can talk, but they cannot put those words into action. Which makes me realise that people can just talk but they...like the example I gave you earlier, whereby one might say, "...instead of sitting at home like you are doing, if you could do other things such as mending bags, and shoes." But it is clear to this person that I have no means [capital] to get such a thing started. You see. Those people are the ones who should be saying, "Here is something, now do this." You see now,* (Urban p. # 9-8).

An HIV+ participant also cited a poignant example of unhelpful support, one that would make anybody feel shunned. One of her husband's brothers never alighted from his car all the times he visited them.

*[W]hen he comes, he does not get out of his car. He stays in his car, and we have to go out there to greet him, and they go back. There is never a day that he ever came out of his car,* (Urban p. # 7-10).

All incidences of perceived unhelpful support could be interpreted one way or the other. It all depends on one's perceptions. Although some people might realise that they are not giving genuine or helpful support, some might be doing so out of naivety.

## **Resilience and Coping Strategies**

Given all the burdens and stresses associated with caregiving and attendant social interactions, it is imperative to re-look at the participant's experiences and see how they are able to make it from one day to the next. Also, given the paucity of resources from the government, non-governmental organisations, and community support networks that has



been discussed above, it would be important to look into other protective factors that are available to caregivers.

According to Reid et al. (1995) "Resilience is the capability of individuals and systems to cope successfully in the face of significant adversity..."(cited in Stewart et al. 1999: 1). It is the protective factors/coping strategies that enable caregivers to cope with the adversities of deprivation, distress, AIDS, discrimination, stigmatisation and caregiving responsibilities that are important for us to explore. The coping strategies that I will discuss comprise individual, family, as well as community strategies. The network support systems (both formal and informal) that I have just discussed above, even though not enough to meet caregiver's needs, still make up a major part of coping strategies used by participants in the study.

### General and other individual strategies

Earlier on I presented evidence about how PWHA avoid telling their caregivers the true nature of their disease, as well as caregivers who do not want to come out in the open to say what their patient is suffering from. Largely, hiding the truth is done to avoid the kinds of public/social reactions already discussed above. This is their other way of dealing with the stigma, rejection, and perceived shame surrounding AIDS. Related to this mode of coping, we also have caregivers or patients that apportion blame for the disease to witchcraft. These are both negative coping mechanisms.

*The patient is saying that she was bewitched. She is not admitting that she has the disease.... [S]he is refusing to accept that she has got the disease, blaming everything on witchcraft....[L]ike I told you in the last interview, the patient used to refuse to accept that she has this disease, that she was being bewitched by her in-laws. [She says], "My in-laws hate me and they are the ones that are bewitching me, so I do not have this disease..." (Urban p. # 12-2).*

Once the community 'knows' one is suffering from a disease related to witchcraft, it is hoped the sick person would not fall prey to the stigmatisation associated with prostitution or promiscuity. Somewhat related to this is the act of apportioning blame to God. In *Shona* culture, diseases, such as flu or colds, are natural and caused by God. Therefore, when one has a natural disease, there is no stigma attached to how they got it, or its nature. Therefore, one might attribute AIDS to the acts of God as a way of avoiding



stigma, or as a way of convincing themselves that 'it is okay'. Here is what a participant said she told her sick daughter when she did not know what else to do about the disease that would not go away:

*There is nothing I can do. If it is a disease that you have been given by God, there is nothing I can do... (Rural p. # 7-1).*

People that belong to orthodox religions, religious sects, as well as traditional religion (or medicine) all believe in the existence of God. The major difference is how these people send their messages to God. As for traditional religion in Zimbabwe, people forward their grievances to God through their ancestors, while the world over, those that are members of orthodox religions have their link in God's son, Jesus Christ. As for religious sects, it depends on each individual sect.

What I found interesting is that, most participants, even those that said that they were not churchgoers, would make references to God once in a while. For example, a participant that had been given advice to tell her daughter to stop sleeping with men by a friend that worked at a hospital they sought medical help said:

*As for me, I just wish God would help me, so that I do not admire 'many things' [i.e. having the desire to sleep with men], (Rural p. # 7-1).*

Therefore, a belief in God, regardless of one's religion emerged as one of the coping mechanisms. God is the one that determines people's fate, including PWHA. As a result, there were numerous references to God as the one that would decide to terminate the patient's life, therefore a caregiver was powerless to do anything else but to leave everything in God's hands. Apart from other general references to God, here are some that are more related to God's powers.

*If God should decide to do as he wishes... (Urban p. # 11-1)*

*In the case where God might decide to pass his judgment... (Urban p. # 12-3).*

*I put everything in God's hands... (Urban p. # 11-1).*

*Leave the matter in God's hands... (Urban p. # 13-3).*

Other individual coping mechanisms included: having positive thoughts, alcohol, and acceptance of the situation. A participant that reported getting overly stressed out by his sister's illness said that "[i]t was alcohol that helped [him] cope..." (Urban p. # 1-7). He went on to say, "...like me, I end up forcing myself to drink beer..." Participants that



were HIV+ and had 'come out'; both caregivers and HBCW were involved in AIDS awareness campaigns. A participant (caregiver) that was involved in these campaigns indicated that these talks enabled her to cope.

*I also go around talking about living positively with AIDS and this has helped me deal with the situation, and it also opens my mind, and as I talk about it I accept my situation and that of my husband's. And we [also] get to hear more information from other people as well, (Urban p. # 7-10).*

Apart from these individual coping strategies, interviews with participants revealed other family and community level coping strategies. The major ones are: traditional religion, orthodox western religion, new religious sects (faith healers), mutual self-help groups, and AIDS support groups. While a few participants resorted to only one of these strategies, most seemed quite eclectic in the manner in which they used them. For example, one participant indicated that they received advice from neighbours on consulting "... faith healers...so that they can examine what exactly it is, not only rely on western medical doctors, but also traditional healers," (Urban p. # 10-1). Another participant whose account portrayed similar eclecticism, but involving three of the strategies said:

*I tried [traditional medicine] but it didn't work. Then I decided to turn to the church...then I went to the clinic...[W]e go to the church because, for things to work at the clinic it depends on one's prayers, right? If you go to the clinic and you don't pray there is no benefit....Our church [Roman Catholic] says we can go ahead and use it [i.e. traditional medicine], but do it in private...So our church is good in that way, (Urban p. # 4-5).*

However, here is a discourse that clearly portrays the belief in trying out many things, in the hope that one of them, or all in combination might work.

*[O]nly that my sister is not much into traditional medicine, but when she got seriously ill, around the last time you came here, I told her that she could continue taking her tablets, but we needed to try traditional medicine because amongst the many different medical systems, we might come across some that can work better in combination. So she listened to me, so sometimes I use traditional medicines on her, (Urban p. # 14-4).*



## Traditional medicine

When we talk of traditional medicine, we enter the realm of a complex traditional belief system whose language and philosophy are the purview of traditional healers.<sup>16</sup> One has to believe that the aetiology of a particular disease and how to tackle it could be better handled by traditional doctors in order to consult them.

*I heard my mother-in-law saying that some traditional customary practices and beliefs ('chimwe chizezuru chinogona kudaizda denda irori') can bring forth this disease. And she was advising us to consult with spirit mediums so that they can explain the cause, from which we would then be able to decide the appropriate type of treatments. So we are still in the middle of planning these things, (Urban p. # 14-4).*

More than fifty percent of the participants indicated that they had tried traditional medicine once or more times, in the struggle to deal with their patient(s)' illness. There was no distinction between urban and rural participants in belief and use of traditional medicine. While some had consulted traditional healers, some had consulted and received from other lay people, medicinal herbs. For example, one participant indicated that she used to cook "...porridge in the morning, before everyone goes out..." for her family, "...with traditional herbs [and] everyone would take it, from the father all the way down...for making the body strong..." (Urban p. # 4-5). Another talked of a friend that went to her rural home to get some traditional medicines for her sister, "...and the diarrhoea stopped," (Urban p. # 12-2). And yet another participant reported about the herbs they had sought from a layperson that lived in another village, for their father's hiccups, and "...they stopped for a while each time soon after giving him, but would start again after some time," (Rural p. # 2-1).

Most participants indicated that they had received information about traditional medicine from network members. While this is informational support in itself, consultation of traditional healers also consisted of another form of social support, instrumental and emotional.<sup>17</sup> Therefore, a number of participants indicated that they liked traditional medicine, and money for the services was the only problem.

*I like traditional medicine...just that these days money is a problem, especially when you are not working... (Urban p. # 15-5).*

*Isn't it for you to go to a traditional doctor you need money?...But if you happen to have a friend that knows these herbs they can just help you (Urban p. # 4-5).*



*Right now there is some traditional herbs that my sister sourced from someone that lives in St. Mary's there. She was saying it could make these sores dry. But right now she cannot go back because she has no money to pay for another portion, (Urban p. # 12-2).*

Apart from money problems, due to the denigration of traditional medicine by missionaries at colonisation, public perceptions about traditional medicine have generally been negative, at least in public for most people. Therefore, this is a coping strategy that is usually recommended in confidence. Utilisation also happens to be secretive with most people.

*But at times either mother or my sister say that they do not want to go to the doctor's surgery, suggesting we try traditional medicine. Sometimes that develops into a crisis that I don't know what to do. [Excited talk, with light laughter] And for me to tell my husband that I am going out [with the family] this way [i.e. to seek help from traditional healers], might seem as if I am getting involved in something clandestine. So that is a problem that I encounter on numerous occasions, (Urban p. # 14-4).*

Utilisation of this coping strategy by caregivers sometimes also depends on the cooperation of the patient. While the two patients reported above would willingly opt for traditional medicine over Western medicine, some patients would refuse. In the case of the following example, the patient's refusal emanated from a conflict in belief systems. But, the caregiver and other kin's belief in the efficacy of traditional medicine would see them persist despite vehement opposition from the beneficiary.

*The problem with this person is that she used to say that she belongs to the Apostolic Faith Church.... And we thought...she would sort out her things within her church.... And now, to try to convert someone like that to believe in traditional medicine, that is a big challenge. But right now since she is merely a patient, we are just doing what we see as more beneficial to her. We are the ones in charge, looking for contacts because we are the ones suffering. She is suffering all right, but she is bedridden. We are the ones faced with the problem of taking buses, going up and down to come and visit her, (Urban p. # 12-2).*

While some participants indicated that they had sought help from traditional doctors without seeing any positive effects on the patient's health problems, some reported a relative degree of efficacy.

*My sister has also been bedridden, because one side of her face had pus coming out, and she was nose bleeding as well. Most of things [were] just too hard for me to cope with, because there came a point where she appeared to have lost her mental faculties completely...I went to a*



*traditional doctor. And in four days things had changed, because she was on the verge of... (Urban p. # 14-4).*

Traditional medicine therefore emerged as one of the major coping mechanisms for caregivers. Since consultations were done as a family, for the sake of hearing the explanations for causes of the illness, which would warrant collective responsibility to tackle, this coping mechanism is at the family level.

The reason this would be a more utilised resource, apart from being more culturally appropriate available and accessible, would be the fact that the charges for services are flexible. Some traditional doctors accept payment upon improvement of the condition; some accept payment at a later time when money becomes available, while some accept payment in the form of livestock, from chicken to cattle.

### Orthodox Western Religion

As I have already indicated above, the church emerged as one of the most important sources of emotional and instrumental support. This is a resource that is cheap, beneficial, available, and easily accessible. Church members reported of receipt of monetary donations, clothes, help with work around the home, but most importantly, comforting words. Comforting words came in the nature of direct words of encouragement, leaving everything into God's hands. But prayers were also the biggest element of the coping mechanism, as well as the belief that God would help.

Some participants reported praying on their own as individuals. Some prayed with family members, while some prayed at church, or the church people came to their home to pray. This makes this strategy an individual, family, as well as community coping mechanism. To illustrate these levels, as well as the usefulness of orthodox religion as a powerful coping mechanism, I will refer to one particular case of an urban-based caregiver.

This participant's life was heavily influenced by her belief in God, and her daily chores and events were embroiled with religious beliefs and prayers. God gave her courage, she said, so she put everything in his hands. Things such as sweeping the house were done while soliloquising, or putting her case to God.

*And sometimes, even while I am sweeping the house I will be praying, asking God to make me strong, "If you do not make me persevere, there is*



*nothing I will be able to do. Look, I have got to the extent where I am getting afraid. And if I get afraid like this, what will I do with my mother? And how is the patient going to take it?" And I see myself developing some courage, because I would have put God in front, (Urban p. # 11-1).*

When she failed to pay a hospital bill for her sister in time, the imminent shut down of their water supply by the municipality prompted her to put her case in front of God, ending, "...God, why have you done this?" Then "things sorted themselves out" when her friends pitched in to help.

*Thoughts were just running around in my head, but things got sorted out in no time, and we paid the hospital bill. So I think there is good work going on, God is intervening most of the time, (p. # 11-1).*

On occasions, this participant and her two friends would pray and fast for a whole day.

*We can choose to spend the whole day praying, putting our grievances to God, asking him to hear our pleas and get inside us...*

According to this participant, "...each and every one of the people I have interacted with more this month are religious people, " (Urban p. # 11-1). In her home with her family they prayed for the patient and themselves most of the time, which made this a family coping strategy. But this also depended on the severity of the illness.

*[W]hen she is seriously ill there will be more of us, but when she is feeling better there is usually my mother and I here [i.e. in patient's bedroom] and my children, then we go to bed, (p. # 11-1).*

The involvement of other visiting church members that came with the local pastor, as well as friends, also made orthodox religion a community coping strategy. What made this strategy easy to fall back to was also the fact that the patient was a member of the Salvation Army, and she believed worshiping had a cathartic effect on her.

*I realised...[patient's name] liked church a lot, she is a member of the Salvation Army, so whenever she was in pain, she would take her hymn book and ask me to open a particular song and help her sing because it made her soul to feel 'freed' ('ndinonzwa moyo wangu kusununguka') and it had a meaning in her life. And we would sing. Or she would just say she wanted to pray on that particular day, and we would give her the opportunity to pray. And mother would pray, and my sisters would pray. And there are also times when she would ask us to call the pastor to come and pray for her because she said she felt a 'burden' within her. When I told this to the pastor, he would ask her what the burden in her was, and asked her to feel free to tell her relatives whatever was troubling her. So, the pastor would come and work with me. On Thursdays, he would come with the women from church ('madzimai*



*eruwadzno') and pray in here. And you could see that she [i.e. the patient] was quite happy about that, (Urban p. # 11-1).*

### New religious sects: Faith healers

There are numerous new religious sects that have sprouted on Zimbabwe's landscape in the last two decades, with disgruntled members constantly splitting up to form their own new churches all the time. The most common one is one known as Vapostori from the Johanne of Masowe Church. One of the ways these sects differ from orthodox religion is their use of 'holy' water to cure illness. The other, and more fundamental one is their explanation of causes of illnesses. While orthodox religion does not believe in witchcraft and other traditional/customary explanations, new religious sects' followers, who proclaim a brand of Christianity, are frequently caught up in witchcraft rituals. They also believe in the 'holy spirit', which possesses them and enables them to diagnose people's problems. These attributes placed them in between traditional religion and orthodox religion.

*We sometimes visit faith healers, and they give the [patients holy] water. And those that say they can take out [foreign objects purported to be inside the body allegedly put in through witchcraft], they also take out, (Urban p. # 10-0).*

About a third of the participants had utilised the services of faith healers, most of them being rural dwellers. Although friends and relatives referred most participants, only two indicated that they were members of the sect they visited for help, while one of a participant's patient, a daughter, was a member. Most of the participants that sought the services of faith healers indicated seeing improvements in the patient(s) condition.

*Yes, it is helpful a lot...she gets better after going there...They [also] come quite often, different people come all the time...about once per week, (Rural p. # 5-1).*

*We once went to the Apostolic Faith Church at...and a prayer was done for her...Sometimes it appears to be helping...sometimes you can't help thinking it is not helping, because after the illness has momentarily stopped, it comes back again more seriously, (Rural p. # 7-1).*

Apart from taking her HIV+ daughter to faith healers, the participant 7-1 also once took her son, to another faith healer.



*So he would give us water that my son uses, and a prayer. The water was to come and wash with. He was also supposed to drink some of it, together with cooking oil...and he was told that might make things work well for him. We came back and he started to use the water as directed, and he is convinced that things are getting better, (Rural p. # 7-1).*

Due to fear of people's reactions, this participant "...had just left quietly" with his son, and on subsequent visits, "...he [would] just leave the house quietly and go to that 'church' to have them work on his therapy ('achienda kunoshandirwa ikoko'), (p. # 7-1).

The following case, however, illustrates how faith healers are used as a means to cope with social problems or conflicts between relatives. Here, witchcraft was diagnosed as the cause of death of the participants' mother three months before, as well as for the current illness of the father. The uncle, and later an aunt that was also a member of a sect suggested to, and brought this family to faith healers for consultations. This was a family that had been asked to move off the land owned by their grandfather (i.e. father's mother's brother), where they had lived for more than ten years. This was the reason given for the illness:

*And they say the reason why he is sick is that these people want you to move away from this land so that they can take their land. And they are the same people that sorted out things so that our mother would die as well. Because mother got sick while she was here, and they told us that she must go to her homeland in Chinhoyi. The reason for that was; they knew if she died here and got buried here, our family would not be able to move away from here. So they thought if she died somewhere else they would be able to get us off the land, (Rural p. # 2-1M).*

This explanation given by faith healers was linked to the sick father's dreams that had images of death, connoting a presence of supernatural forces, and lack of consensus among his ancestors were an indication of a balance of chances between death and survival.

*Even father was saying that he dreams about his dead father in a water well where he was calling him to come down to join him.... Later he dreamt about our grandfather from here, who is also dead, together with his dead sisters, as well as that grandmother's mother. He said there were three women, and two men...The men were saying, "Come." But the grandmothers were saying he mustn't come, they were refusing, (Rural p. # 2-1M).*

Survival, however, according to the faith healers, would depend on acting on their suggestions.



*[They told us], "...for him to remain alive longer it is necessary for us to conduct a church ceremony at your home. After that, then we can remove from your home whatever evil things ('chitumwa') were placed by those people from grandmother's family; that will enable you to relocate peacefully from this home." Because they explained to us that, whatever jinx our grandfather put here, has already killed mother, and it also wants to kill father. After it kills father, then it comes to take the eldest son and eldest daughter, (Rural p. # 2-1M).*

This discourse was particularly disturbing, coming from a teenager and his elder sister [i.e. the first born child], the persons predicted to be the next targets of the jinx. The stern look on the young man's face showed fear and helplessness. If this family did not do what the faith healers said needed to be done; the jinx would "...kill father, them go back to the owners, and subsequently come after us after we have moved." The participants later indicated that they had, through the guidance of their aunt, brought the faith healers to perform the cleansing ceremony.

*She is a member of the sect, so she brought them here. They came and removed the things that were here, offered a prayer, and gave him [father] some water, (Rural p. # 2-1M).*

Unfortunately, these participants' father passed on three days after our last interview.

### Mutual aid/ self-help groups

Mutual aid/ self-help groups also emerged as a beneficial coping strategy for people facing common problems. They are a community coping strategy. In this study, they came in the form of burial societies, support groups for PWHA, and groups locally known as 'societies'. The roles of support provider and support recipient in these are mutually shared among the members, entailing high levels of reciprocity. Burial societies benefit every member equally, and the contributions are uniform. The 'societies' whereby people pull resources for the sake of helping each other buy household items of food items are also meant to benefit every member equally. Both groups provided participants with instrumental and emotional support.

There was only one participant that indicated that she was a member of a semi formal burial society. The other two participants came from communities where helping out at funerals was just an impromptu drive to source resources from other community members. However, the continued use of this strategy at every funeral makes it an



effective coping strategy because essentially the same resources (e.g. corn meal and monetary donations) are collected for a bereaved family.

Only one participant from the urban sub-sample indicated that she was a member of a support group for PWHA. None of the rest of the urban participants' patients belonged to any support group. From the two rural sites, participants had registered with the Mother of Peace Orphanage to form support groups two months before, but funding for income-generating projects from the national AIDS levy, through the ZNNP+ had yet to be disbursed. The one urban participant that was a member of a support group indicated that this was an effective resource for emotional support.

*Relatives now refuse to have anything to do with us...They do not visit anymore...However, we have joined support groups....and these have helped because you feel you are not alone in this kind of situation. You get to hear some experiences [from other people] which are even worse... (Urban p. # 7-1).*

However, the semi-formal arrangement reported by one urban participant seemed to be a more reliable and stronger coping strategy,

*[O]n this street, we made an agreement that whenever one has a funeral at their home, each one contributes a certain sum of money, and corn meal....[W]e ...contribute corn meal and money to allow whoever has been affected to help themselves (Urban p. # 11-1).*

'Societies' are groups of families that decide to come together for the sake of helping each other on a consistent basis. Each family has a turn of receiving the monthly contributions from members. There is usually a prior agreement as to what is bought for individuals, so that there is equality in contributions as well as benefits. While two participants indicated that they were members of some loosely formed groups that helped each other with monthly 'rounds' (contributions), one participant indicated they had received a loan from the 'society' their sick father was a member. However, only one participant belonged to a more solidly formed, long-time running 'society' of four members.

*We do have a form of cooperative, whereby we give each other utensils. So, we meet at the house of the person whose turn it is to receive the utensils. It's just like a mini party, then we give each other whatever we have brought and that's it. That is a good time for us, because we also pray while we are in that gathering, (Urban p. # 11-1).*



According to this participant, this group of friends was an effective supplier of both instrumental and emotional support. This was possible because these were long-time friends, and all were members of the same religious denomination that prayed together as well.

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## Notes

1. Davis (1992:145) gives the ethnographer's concerns as: semantic and communication phenomena, and the intentions, purposes, motives, goals, attitudes, thoughts and feelings of those whose culture is studied. An effort was made to include these wherever possible in this study.
2. Cresswell recommends the use of analytic claims (1998: 183). He quote from Emerson et al. (1995), who indicate the utility of "excerpt commentary" units, whereby an author incorporates an analytic point, provides orientation information about the point, presents the excerpt or direct quote, and then advances analytic commentary about the quote, and then advances analytic commentary about the quote as it relates to the analytic point.

According to Cresswell (1998: 183) short, eye-catching quotations verify text, while embedded quotes "... provide specific concrete evidence, in the informant's words, to support a theme."

3. For instance, if a daughter-in-law takes care of a sick mother-in-law or any other member of the in-laws' family, she has to be compensated before she dies, either by cash, goat, or cow. Similarly, if she raises any child from her family of marriage (in her home) other than her own, she has to be paid 'chiredzwa' (compensation for rearing the child).

Also depending on the length of the time she raised the child, payment can amount to a cow. If she happens to die before this compensation is paid, the in-laws will have to drive the cow/cattle to the parents' home; otherwise calamity will befall them. As they say in *Shona*, her spirit will come back to haunt the family, ('*anomuka ngozi*').

4. The fact that there was no male primary caregiver for a daughter did not surprise me. Apart from the fact that the sexes are different, there is one traditional custom to note. In *Shona* culture, a daughter or a sister is supposed to be well respected by her brother or father, and is often addressed as '*ambuya*' (which means 'mother-in-law', and mother-in-laws are revered in *Shona* culture). This comes from the fact that a daughter's daughter, or sister's daughter is a niece ('*muzukuru*'). Sisters and daughters also address their brothers and fathers as 'son-in-law'.

Nieces and nephews, grandmothers and grandfathers, and aunts are people that one has joking relationships with, whereby grandmothers and aunts jokingly call nephews or grandsons 'my husband'. However, traditionally, nieces have always been regarded as potential 'wives'. There is a possibility that this can happen; but nowadays it only happens in theory, such that it just remains symbolic. Apart from the direct and positive utility of joking relationships, these father-daughter, brother-sister relationships whereby they call each other 'mother-in-law' or 'son-in-law' served the function of curbing incestuous tendencies. There is a *Shona* proverb that sums it all up, which goes, '*Muzukuru mudonzvo wepwa*', which means 'A niece is a walking stick made out of a *sugar reed*' [a sweet seasonal plant, but much thinner and less sweet than the perennial sugar cane]. Literally, this



means when you get tired of walking, you can once in a while take a rest while you eat some segments of the sugar cane. Hence mothers of nieces, or mothers of the 'sweet reeds', command respect.

5. In *Shona* culture, mentioning the names of genital organs in the company of people other than age mates or friends of the same sex is considered taboo. To do that is a show of disrespect. For this reason, health campaigns, such as condom use, are difficult. For this caregiver, then, seeing a brother's genitals is unthinkable. That is what society expects of her.
6. In 'Shona' culture, visitors are supposed to be fed after arrival. Refusal to eat can send wrong signals, such as: you are afraid of getting bewitched through eating the food, lack of respect, or that you are setting the stage for not reciprocating when they come to your place. With a patient in the home, many people come to visit and, it was during those times when the caregiver cooked for visitors that the patient also asked for food, as if he hadn't eaten before the visitors came.
7. Role conflict is hereby used in the sense "...when a person finds he or she is playing two or more roles at one time that make incompatible demands..." (Abercrombe, Hill & Turner, 1994:362).
8. Women that get married into a Shona family have a serious and joking relationship with their husband's sisters and female cousins. The joking relationship also involves calling a spade a spade in jocular ways, as well as light-hearted humour. On the serious side, it involves emotional and informational support, because the wife can go to the aunts (sisters-in-law, 'anatete') to seek advice and help with her marital problems. The situation explained here is a case of the more serious side, in terms of the acknowledgement of the amount of work. By saying 'you are putting us to shame', the aunts are also acknowledging their failure to help a close relative whom they are, by custom, supposed to be giving support.
9. Discrimination related to government policies has been documented in a literature review by Busza, (1999: 2).
10. *The [Zimbabwe] Herald*, (2000) "Focus Now on How National AIDS Trust Money Should Be Spent" 16 May, p.1-2 (online).
11. In *Shona* society, which is patrilineal, sons almost always settle in the land occupied by their father, and inherit from their fathers or paternal grandfathers. This maternal grandfather would have his land inherited by his sons; but it is never unheard of that one could inherit from a maternal grandfather. Therefore, one gets suspicious of this grandfather's motive, especially when he decides to evict a family that had been living on that land for more than fifteen years, after the parents have succumbed to AIDS.
12. According to Abercrombie et al. (1994: 348) "Mutual reciprocity between actors A and B is contrasted with univocal or directional reciprocity in which A gives to C in return for what A receives from B.



13. In *Shona* custom, people with the same totem are believed to be descendants of the same ancestor, and are therefore related, and the more reason why people with the same totem cannot marry one another.
14. In this study I took social support to mean the "...interactions with family members, friends, peers, and health care providers that communicates information, esteem, aid, and emotional help," (Stewart's, 2000: 85).
15. This takes us back to the issues that I discussed in Chapter IV, regarding the general economic climate surrounding participants and their network members. This is the environment depicted by the inner rectangle labelled "Poverty" in both *Figure 1 & 2*.
16. There are many types of traditional healers in Zimbabwe, and here are just few major categories. Spirit mediums (or spirit diviners) are believed to have the ability to communicate with ancestor or alien spirits while in a state of spirit possession (Chavunduka, 1986). They are mainly concerned with causes of illness; hence they specialise in diagnosis and (in most cases) refer patients elsewhere for medicines. Herbalists are not concerned with the causes of illness but the treatment of physical symptoms. People with symptoms come directly or are referred by spirit mediums. Then there are spirit mediums that are also herbalists, who carry out a diagnosis while possessed and also treat patients. Then there are general diviners, who are also experts at carrying out a diagnosis by the use of bones [small pieces of wood, stones, shells, etc.] (Chavunduka, 1986). Then there are traditional midwives, who are most likely to be well versed in traditional herbs that are relevant in their field of work. According to Chavunduka (1986) each category has its own specialists; other specialists concentrate on children's diseases, others on women's illnesses, still others on mental disorders and so on.
17. African healers make little distinction between body, mind and spirit; they perform a purgative and cathartic function in order to reintegrate patients into their society. This is a process that would be observed as a provision of emotional support. Also since traditional practitioners offer both social and mystical explanations for the causes of illness, these explanations would also be expected to enable caregivers to cope with their current adversities.

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## CHAPTER VI

### DISCUSSION, CONCLUSIONS AND IMPLICATIONS

This exploratory study used ethnographic and phenomenological methods to explore the experiences of caregiving (for PWHA) and social support. This qualitative approach, utilizing interviews, demographic data, and observations yielded data pertinent to the description of the contextual issues in Chapter IV, as well as the analysis and description of caregiving and support experiences in Chapter V. In Chapter IV, a working model evolved from the data to explain the contextual elements affecting family caregivers of PWHA. This working model was developed further in Chapter V, and will be used to organize discussion in this chapter. A summary of findings will then be presented together with conclusions. Following these, implications for health promotion, and intervention will be discussed. The limitations, future directions for research are presented next, followed by my personal reflections on the research process.

#### Discussion

##### Demographics

The social demographics from this study revealed that the majority of caregivers were women. Similar findings have been noted in Zimbabwe (Woelk et al. 1997; Mushonga, 1998) and elsewhere (Sharpe et al. 1994; Kaleeba et al. 1994, Harrison (2000). Although a relationship has been found between gender and social support elicitation and provision (Flaherty and Richman, 1989), the sample in this study was predominantly female to be able to provide any meaningful comparisons between female and male caregivers.

##### Context: Poverty

*Figure 3* is bounded by two borders, of which the inner one is labelled 'Poverty'. There was overwhelming evidence, in the nature of: unemployment, lack of stable family income, lack of housing tenure, lack of proper housing, and lack of household amenities,



lack of livelihood resources, to warrant treatment of poverty as a meta context affecting caregiving experiences and network support flows. There is widespread evidence in the literature on the linkages between poverty, and ill health, particularly AIDS (WHO, 1999; 2000; UNDP, 2000).

Participants complained about the deteriorating standards of living due to the high cost of living and unemployment, issues that have been reported by Kanji and Jasdowska (1993). In this study deprivation/ poverty played a crucial role of circumscribing caregiving responsibilities, as well as support receipt and provision, a finding that has been reported for Zimbabwe (Mushonga, 1998; Woelk et al., 1997) and other countries (Baylies, 1999; Okongo et al., 1992; Trubey et al., 1997; Vera et al., 1997).

### Context: Culture

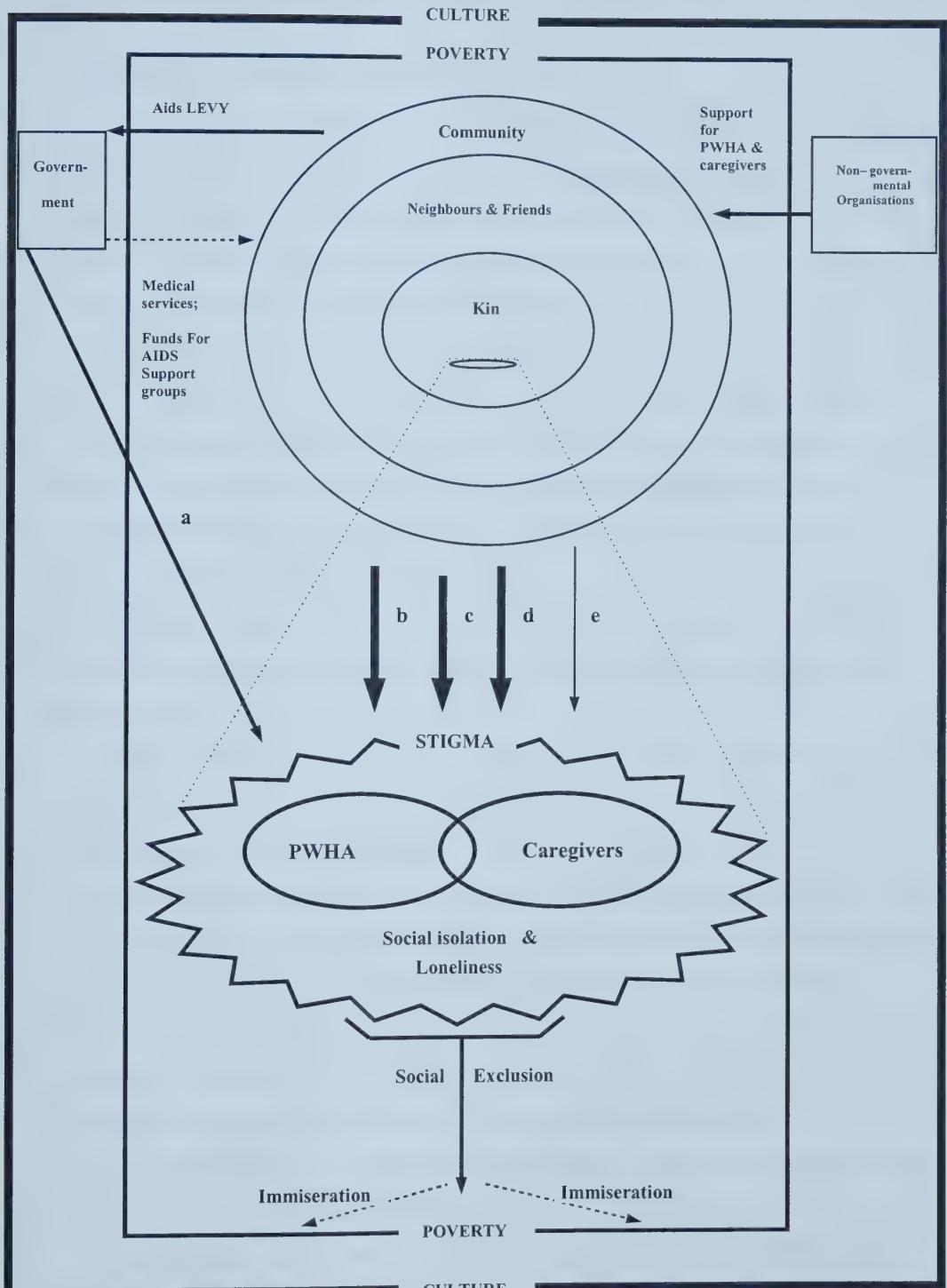
Culture, which makes up the major meta context in this study, influencing everything to do with caregiving, support processes, and social reactions to AIDS, forms the outer boundary in *Figure 3*. Culture was so pervasive as to also influence kinship relations, role assignment, and caregiving norms. Its relationship to some of the variables in *Figure 3* will be dealt with below. For now, it is important to only mention that other scholars have underlined the need to include environmental variables (Sarason, Sarason & Pierce, 1997; Antonucci, 1985), particularly the cultural context, in the evaluation of social support exchanges.

### Caregiving and well-being

Evidence from this study points to a crushing burden of caring, juggling between caregiving and other household duties, resulting in job overload and role conflicts. The burden of duties also kept caregivers isolated from other community activities, leading to loneliness. Heavy workloads and the burden of responsibilities were perceived to result in mental stress and physical problems by caregivers. Much of the research into caregiving has also regarded it as a stressor, and documented the negative impact it has on caregiver health and well-being (Rosenthal, Sulman and Marshall, 1996). A related issue that was found to cause stress among caregivers that has been overlooked in research on caregiving for AIDS patients is the issue of patients verbally abusing caregivers as they



**Figure 4: Dynamics of Social Support and Exclusion Among Family Caregivers of PWHA**



a: early discharge of patients  
b: gossip & rumours  
c: loathing  
d: shunning & ostracism  
e: social support



try to cope with the disease. This interaction partly determines the relationship between caregiver and patient, which is the intersection in the Venn diagram.

### Social reactions to AIDS, PWHA and Caregiving

This study found evidence of a wide variety of social reactions to AIDS. I have labelled these reactions 'a' to 'd' in *Figure 3*, where the caregiver and patient (in the Venn diagram) are shown to be tainted with the air of stigma (i.e. the jagged surrounding). However, one other important reaction noted besides these four is that of caregivers themselves being afraid to catch AIDS from the patient they are looking after. This reaction did not have extensive negative repercussions because it was tempered by the strength of kinship ties. The first social reaction 'a', concerns the early discharge of PWHA from hospitals so that they can be looked after at home. This results in perceived discrimination by caregivers and PWHA. This negative consequence of patient discharges contributes to the overall stigma surrounding AIDS, because everyone believes that a patient discharged from hospital is not worth caring for because they are dying. This is a pathway to stigmatisation that has not been extensively explored in literature, but has been reported in Busza's (1999) review of literature pertaining to Southeast Asia.

Within the community, the most common social reactions that were found in this study are: gossip and rumours 'b', loathing 'c' and shunning and ostracism 'd'. Although these reactions were towards the patient and AIDS as a disease, they affected the caregiver to the extent that kin, and other members of the caregivers' networks visited less. There have been widespread reports of stigmatisation and discrimination of AIDS patients and their caregivers, leading to isolation and loneliness in the literature (Mutetwa, 2000; Stewart, Hart and Mann, 2000; Stewart, 2000; Thompson, 1999, Kalondo, 1996; Hwayire et al., 1996; Stewart, 1989; Casaux & Reboreda, 1998; Busza, 1999). However, the link between social reactions and social support 'e' is one that has not been explored fully in the literature. When members of the social network visited less, that meant less social support flowing in.

The thickness of arrow 'e' in *Figure 3* is therefore deliberate, indicating withdrawal of support by network members. Stigma surrounding AIDS/PWHA, which is



layered upon pre-existing stigma attached to prostitution and promiscuity, also reported by Herek and Glunt (1988) and Busza (1999), makes support providers want to know the disease one is suffering from first. Suspicion that it is AIDS results in the withdrawal of support. Avoidance of the use of the word AIDS in caregivers' discourses is a direct reaction to the stigma attached to the disease. This study has surpassed existing literature, in as much as it explored the emic perspective, what it feels like to be stigmatised and not supported.

### Meta contexts and social support

Cultural norms played a significant part in mediating kin, and distant kin's obligation to provide support. Although these obligations were tempered by the current state of deprivation/ poverty as also observed in Uganda (Okongo et al. 1992), kin still emerged as the more reliable source of instrumental support. Literature on African societies abounds with evidence that extended family ties remain significant in social life (Comhaire, in Gutkind, 1963; Skjorberg, 1989; Colson, 1971). Woelk et al. (1997) have noted that more than half of the support with patient care for caregivers of PWHA was from close kin.

Cultural norms, in the form of proverbs that instil in people a sense of mutuality, also guided the social rules of support exchanges. Most participants believed in mutual reciprocity due to deprivation caused by the current economic hardships, while a few believed in univocal reciprocity, which is the philosophy underlying the proverbs in question. Most caregivers believed that, due to deprivation, support providers tended to withdraw support from recipients that could not reciprocate, while they themselves failed to reciprocate because of deprivation.

Several scholars have, based on social exchange theory, emphasized the need to look into the issues of reciprocity in social support research (Stewart & Langille, 2000; Kahn & Antonucci, in Antonucci & Depner, 1982; Howard & Hollander, 1997). The results from this study support this position, as well as the assertion made by Clark (1983), that in communal relationships, interpersonal behaviour is more determined by felt desire to respond to others' needs than by exchange principles. Antonucci and Jackson, (1990) also highlight the relevance of the cultural context in evaluating social



exchanges. Further research in other communities not so marginalized and deprived, or the same communities under better off conditions might yield more definitive results on the effect of communal relationships on reciprocity.

### Types of supports

The needs assessment component of the study revealed that caregivers were more in need of instrumental support than any other types of supports, even though they all reported the positive effects of other functions of support. Definitions and appraisals of support also showed a bias towards instrumental supports, and other functions of support tended to be downplayed. This was again the effect of the economic deprivation they were experiencing. This highlights the need for studies to explore issues of needs in the context of culture and other mediating environmental variables. However, the most important finding was that the concept of social support as defined in literature from Western countries is difficult to apply without modifications in other cultures.

Caregivers received more supports from informal sources than formal sources, and, from the informal sources they tended to receive more emotional and informational support than any other type. Again, the mediating variable was the state of deprivation. All these dynamics have not been adequately explored in the literature.

### Peer support and social comparison

Literature on social comparison has highlighted the importance of upward comparison and downward comparison in support dyads (Stewart, 1989). In this study, however, there emerged a different kind of social comparison, one whereby a caregiver thinks, 'I am not alone in this', not the individualistic type of comparison often reported in the literature.

### Social exclusion and imisseration

Having discussed most of the dynamics related to social support among caregivers of PWHA, I would now like to take the issues of social reaction to their final conclusion, which starts with the downward arrow marked 'social exclusion' in *Figure 3*. Social exclusion has been defined as "the process whereby people become deprived, and



the many aspects of the deprivation they face," (Amaratunga, Roy & Stanton, 2000: 10). In this study, I have analysed some of the many manifestations of exclusion facing caregivers and their patients (e.g. unemployment, lack of housing tenure, lack of incomes, deprivation). This is the initial state of affairs before factoring in the dynamics shown in *Figure 3*. The effects of role overload and social reactions, result in social isolation of caregivers and their patients. Isolation is therefore hypothesized to worsen the initial exclusions, a scenario leading to an intensified process of impoverishment that Cohen (2000) has coined immisseration,<sup>1</sup> the process shown by the two broken arrows at the bottom of *Figure 3*. This immiseration feeds back into the meta context we started off with, and, without any steadfast intervention, the AIDS pandemic will cause untold suffering.

### Resilience

Stewart et al. (1999) have highlighted the importance of coping strategies to resilience, while empirical evidence is lacking on how caregivers of PWHA actually cope. While caregivers used different individual coping strategies, the ones that emerged as the most beneficial are those at family and community levels, such as: use of traditional medicine, orthodox church membership, consultation of faith healers, mutual aid/self help groups. While the resort to these coping strategies signifies the important element of resilience, at the same time it highlights the importance of the interactionist perspective, one of the perspectives informing this study (Heaney & Israel, 1997). Symbolic interactionism views social actors not wholly determined by external forces. They shape, adapt and transform structures around them with a view to making them fit their own social lives.

### **Summary and Conclusions**

The refusal of an AIDS support organisation for middle class patients to allow me access to their clients resulted in a total sample of low-income participants, with sub-samples from low-income urban suburbs and low-income rural families. Conducting the interviews in the homes of participants provided an opportunity for a bird's eye-view or



insider's view of the living conditions of these families, complementing the heart-rending narratives of these low-income caregivers.

According to UNAIDS, HIV positive women now outnumber HIV positive men in Africa, and, one of the organisations that linked me up with participants supported more HIV positive women (than men) with their home-based care program, and treated more HIV positive women (than men) in their palliative unit in 1999. The fact that women are also the majority family caregivers is an appalling revelation of the extent of the marginalisation of women in Zimbabwe. Women who are already saddled with the double burden of social production, and care-taking, are forced by AIDS within the family to reallocate their labour from other income generating activities outside the home to care-taking almost full time. Also noteworthy in the sample was the overrepresentation of both caregivers and patients whose median ages were 34.5 years and 32.5 years (mean=35 years and 42 years) respectively. This affirms the position that AIDS claims the lives of people in their most productive years. Firstly, the adult family member with AIDS compromises the household's resources as the functional capacity to work is reduced, medical expenses increase, and income is lost. Also, the diversion of human resources from productive agricultural activities and other income generating activities, to caregiving, also erodes the quantity of the available workforce (particularly at family level), and income levels. Ultimately, this has an effect on economic development at national level.

It has been said that in order to understand the depth of poverty in Africa, one has to live it or visit people suffering from real poverty (WHO, 2000). Considering that Africa has the most number of AIDS cases worldwide, it is perhaps understandable why some would say that AIDS is a disease of poverty. The median gross household income for caregivers in the sample was ZW\$1,000 (mode=ZW\$500). The official exchange rate is CDN\$1 = ZW\$35, and, considering that ZW\$35 could not buy two loaves of bread, it is not hard to imagine how far ZW\$500 could go in relatively large families (mean=6), that also had to provide palliative care and 'special' foods for their patients. The circumscribed and precarious sources of income ranged from vegetable vending, other informal sector activities, production and/ or sell of agricultural produce, to unreliable remittances from kin.



In both sub-samples, only one rural participant had formal employment, and each of the rest of the households had no other gainfully employed family member. None of all the unemployed caregivers had relinquished their job in order to provide care to a family member full time. Only two, one male and one female participant, had ever been employed, as a domestic servant and civil servant respectively, and the former was made redundant, while the latter resigned for health reasons. The rest were either victims of the national record unemployment rate of over 55%, as well as cultural practices that have kept women marginalized from formal employment. Employment is associated with steady incomes, stability, and predictability.

Most of the patients had tuberculosis (TB) and were under treatment. TB alone accounts for about 40% of all AIDS deaths in Africa (WHO, 2000), and, it is a disease that has been traditionally associated with poverty. The overcrowded and unhygienic conditions in most of the homes are conducive to its transmission between HIV patient and other household members. However, since TB medication (provided free of charge by the government) has to be taken over several months, it is its side effect of increasing one's appetite that becomes problematic for cash-strapped caregivers who do not know what else to do.

Despite extensive efforts in AIDS awareness campaigns, which are hoped to help demystify the whole issue of AIDS and to impart accurate messages, which decrease fear, ignorance and prejudice, stigmatisation of AIDS was observed to play a key role in reducing social cohesion in communities. First, most of the female patients whose husbands had died of AIDS were subsequently rejected by their in-laws, and were residing and receiving care in their families of origin. In many cases, they came back with their young children, which became additional mouths to feed for the caregivers.

However, more importantly, stigmatisation resulted in social exclusion of the patients as well as caregivers, resulting in their social withdrawal, social isolation and diminished social support from significant others. Stigmatisation also forces patients and caregivers to conceal the nature of their disease from 'outsiders', even next-door neighbours, a move that also works to reduce support from potential providers who might have chosen to support if they knew the nature of the disease.



The inadvertent consequences of structural adjustment programmes and economic/trade liberalization policies in the developing countries are no longer an enigma. That the adoption of these policies in Zimbabwe has thrown many households into deprivation and despair is unequivocal. These policies have resulted in reduced per capita public expenditure in the service sector and an ever-soaring inflation rate above 40%. Cuts in health spending have translated into early hospital discharge of AIDS patients, leading to more burdens on family caregivers. As a result, many households are increasingly finding it very difficult to maintain their levels of domestic consumption and securing their general welfare, but most importantly their patients'. Most low-income households now face a day-to-day experience of falling standards of living, reduced capacities for personal and social achievement, and worsening prospects for the future.

Therefore, at a time when the burden of care for the sick demands the attention of the traditional network of social and political capital, these resources were found wanting in this study. Zimbabwean people, like other African Societies, have for a long time survived on elaborate social support systems and community responsiveness based on the extended family structures, rather than individualism. But economic austerities and the struggle for survival have tempered these culturally relevant, traditional and practical support structures, resulting in either withdrawal of, or limited support to network members. Hence, general abject poverty, in conjunction with stigmatisation in the communities studied, has also contributed to social exclusion and isolation of family caregivers and PWHA. Some caregivers are also unwilling to go out of their way to seek social support because of fear of indebtedness, since abject poverty incapacitates their ability to reciprocate.

Therefore, the impact of both poverty and AIDS has had a disintegrating and destabilizing effect on the traditional African extended family system. What caregivers need most at the moment, practical (instrumental support), is not forthcoming from the social network members. However, support resources from the government are even more conspicuous by their absence. The few non-governmental organizations supporting those infected as well as others affected with AIDS were observed to be overburdened, and concentrated in urban areas. This urban bias further reinforces the traditional urban bias in service provision, which leaves the rural populations more marginalized.



Ironically, most people sick with AIDS move from towns to their rural homes in the end stages of AIDS, to die there. In this study, five out of eight patients had done so. Moreover, at this end stage of AIDS the patients need more support. Emotional support, easily affordable for network members, and which is also crucial for caregivers, is either withheld by network members, who saw AIDS as a punishment for one's mischief, or provided but with a drawback in the form of apparent insincerity, depreciatory remarks and rumours (about the nature of the disease) that are spread in the community by people who would have visited to see the patient(s).

What also emerged from this study is that caregivers are faced with an insuperable task of providing 'quality' care with scant resources, which is a potential source of burnout. The work overload, emanating from the combination of caregiving responsibilities and other household chores, plus the emotional burden of caregiving do not augur well for the psychosocial and physical health of women. Furthermore, an unhealthy material environment, the worries and insecurities of daily life and the lack of supportive environments all have an influence on health. Morbidity in the caregiver translates into diminished quality care for the patient. Poverty and unemployment have taken centre stage, causing continuing anxiety, insecurity, low self-esteem, feelings of helplessness and powerlessness, social isolation and lack of control over caregiving and life in general.

Care for AIDS orphans and AIDS awareness education, and financial support for support groups for people with AIDS, into which great effort is being channelled are all laudable causes. However, since AIDS and poverty have a bi-directional relationship, and poverty compromises the quality of family caregiving, these seem like contracted and ephemeral solutions. Far-reaching and upstream efforts to strengthen social capital, and to stem the synergistic interface of unemployment, poverty, and AIDS need to be looked into with a view to providing safety nets as well as springboards to offset the earlier disadvantage faced by low-income families. Interventions aimed at the development and strengthening of sustainable social capital, quality of life, and health, will go a long way towards sustainable human and economic development.

There also needs to be development, assessment, and evaluation of the most appropriate and ethical community development oriented interventions with long-term



effects, aimed at facilitating marginalized groups such as caregivers of PWHA and communities to gain greater control over the social, political, economic, and environmental factors determining their health. While geared to help caregivers cope with their psychosocial and physical health, and to improve their self-reliance, these intervention strategies would also allow them to give better care to their patients. In such intervention strategies, issues surrounding AIDS, health issues and poverty would be treated holistically in order to ensure the empowerment of marginalized groups, such as women in general, caregivers, and PWHA. Through community participation, the capacity building process would begin with mapping assets in the form of already existing formal and informal support/ helping systems, resource persons, and traditional knowledge systems in the communities. Such a strategy to development would help to develop more effective coping strategies and strengthen resilience.

### **Implications for Health Promotion**

This research experience revealed to me the gaps in knowledge, regarding the need for a deeper understanding of the circumstances under which family caregivers operate, and the need to work out proactive measures aimed at promoting the health and quality of life of family caregivers and women in general. The study revealed the implications of gender, culture, housing tenure, employment, access to health services, an adequate income, and social support for caregiving and coping. These are some of the major determinants of health (Health Canada, 1999a; 1999b), as well as the underlying exclusions (Amaratunga, Roy & Stanton, 2000) that caregivers in the study faced. A clear health promotion implication of this study is that caregiver well-being and support provision can only be enhanced by comprehensively tackling all the underlying exclusions affecting caregivers

Health promotion is taken to be "...the process of enabling people to increase control over, and to improve their health..." (WHO, 1986, in Institute of Health Promotion Research, 1995:18), as well as "...the socioenvironmental approach to health..." (Labonte, 1993:1). Hence it "... is intrinsic to the social-ecological paradigm and the holistic nature of health in that it addresses both personal and environmental factors in order to improve health potential," (Baskerville, 1988:8). Health promotion



interventions should, therefore, aim to address all the above-mentioned exclusions, which are major determinants of health.

Helplessness and powerlessness were common themes that came out of this study. Interventions would, therefore, be more effective if implemented through community development initiatives that can stimulate empowerment, which is a key ingredient of health promotion (Labonte, 1993; Stewart et al., 1999).

### **Implications for Intervention**

This study has explored how social reactions to AIDS and PWHA (discrimination, stigma, loathing, shunning, gossip) result in the social isolation, loneliness and exclusion of caregivers of PWHA, and how these reactions negatively affect the flow of network support resources. These reactions both directly, as well as through diminished support, affect caregiving experiences. Given these realities, it is pertinent that appropriate measure be taken to boost social support for caregivers as well as reduce negative societal reactions to AIDS. The findings, therefore, have several wide-ranging implications for policy.

These implications address issues to do, first of all, the overall state of deprivation and original disadvantage faced by low-income caregivers. They also address issues of: self-esteem, mitigating the effects of the various social reactions to AIDS, enhancement of network resources and coping strategies. The implications are:

- Increase government funding for health services that put priority on all opportunistic illnesses associated with AIDS other than TB, to avoid 'home-based dumping'.
- Enhancing existing health services and making available additional free basic services (e.g. check ups, and basic prescriptions).
- Include caregivers in AIDS support group activities and funding.
- Equitable distribution of governmental and non-governmental support resources to families, support groups and communities.
- Enhancing services through better integration and coordination of government and non-governmental support strategies in order to avoid an urban bias as well as duplication of efforts.



- Establish regional and district centres for counselling to deal with non-disclosure of HIV status, discrimination and other problems.
- Establish local structures to deal with financial assistance during times of distress.
- Help caregivers develop and enhance individual self-esteem through formal institutional supports so that they can deal with the psychological problems resulting from social stigma surrounding AIDS, and the attendant social isolation and exclusion.
- Establish horizontal links between professional health workers, community groups and family caregivers. Professional workers have access to information and resources otherwise not available in the community social networks.

- According to Moyer, Verhovsek & Wilson (1997, p.98):

*If health promotion projects are to be successfully planned and implemented, a transference of professional expertise to community members may be necessary through more extensive workshops, mentoring, and other training opportunities.*

The other rationale for using professional carergivers is that they are a resource that is already available. This interaction is also expected to equalise professional/ consumer relationships and increase the community's participation in solving health issues.

- Retrain/reorient health personnel to make them sensitive to AIDS issues.
- Enable family caregivers to acquire appropriate knowledge, skills, organizational capacities and a heightened sense of individual and collective responsibility and efficacy in caring for patients through information sessions and workshops.
- Equip community-based health workers, through participatory training and skills transfer, with the requisite skills to initiate, implement, manage, monitor and evaluate priority health programmes and activities together with caregivers in order to increase knowledge and community capacity, as well as handle issues of stigma.



- Involve caregivers and ABHW in policy making health and community development related policies.
- Facilitate the acquisition of skills relevant for the planning, implementation and evaluation of community (social and income generating) projects managed by PWHA, caregivers, lay/peer helpers, and wider community members through community participation, and create the much-needed social safety net. Involvement of people unaffected by AIDS would help to dissolve myths about transmission, create empathy, and facilitate the flow or support resources between affected and unaffected families.
- Fund and facilitate the development and enhancement of self-help/mutual aid groups (e.g. burial societies, 'rounds'/'societies') in order to strengthen family and community protective factors/coping strategies and collective self-esteem. Boosting up community-based social support systems is needed to compensate for the ineffectiveness of government support structures.
- Create employment opportunities to enhance self-sufficiency, reciprocal support exchanges, individual, and family and community competence relevant for dealing with helplessness, powerlessness, and deprivation. Provision of a basic income would be an important action against poverty and social inequalities. This will enable caregivers to move from 'taking care of', to 'caring' for their family members with HIV/AIDS.
- Involvement of church organizations, schools and other civic organisations in campaign strategies in order to bring openness in dialogue about AIDS.

**A more focused utilisation of community-based workers with the aim to build and strengthen community connectedness should be top priority.** The use of indigenous lay helpers in intervention projects has been widely reported in the literature (Steckler et al., 1995; Stewart et al. 1999). It is one strategy of enlisting participation and increasing social support through network interventions. Indigenous helpers can help connect community residents to health programs and organisations. Lay helpers would



ideally comprise of paraprofessionals like HBCW, village community workers (VCWs), traditional birth attendants (TBAs), traditional healers (THs), and church leaders.

All these are natural helpers within communities and are generally well-respected members of social networks to whom members of the community naturally turn for advice, support, and other types of support. A focus on these cadres' contribution to building community resilience and connectedness and, strengthening community health should be more important now in order to combat emerging health issues such as AIDS, and most importantly, providing social support to family caregivers. The respectability that these community members enjoy in the community would make their involvement a potent force to stem the social reactions of loathing, shunning, and discrimination.

**Strengthening of peer-helper support systems should take top priority in order promote social inclusion.** Creation of community development projects, such as income generating projects would allow family caregivers to form dyadic relationships that would provide support to alleviate emotional loneliness through upward and downward social comparison processes. The importance of peer helpers in the provision of emotional and informational support was demonstrated in this study.

**Creation and strengthening of community-based Mutual Aid/ Self-help groups should take top priority in order to stimulate the flow of support resources among community members.** The literature is replete with examples of the use and effectiveness of self-help or mutual-aid groups in developing social network linkages and provision of social support among aggregates of people sharing the same problems/stressors (cf. Minkler, 1998; Heaney & Israel, 1997; Labonte, 1993, 1989; Stewart, 1989). Therefore “the power of the group is in creating that connectedness, the healing of the group is validating that we are not alone” (Labonte, 1993, p.62).

This study has demonstrated the perceived benefits of mutual aid groups in the performing various support functions among caregivers and other community members. Existing mutual aid groups could form the backbone for community development projects.

The involvement of lay- and natural helpers can help family caregivers to create partnerships between self-help groups and local institutions. This would help cast the social network net wider as well as enhance existing networks that are currently small for



informal caregivers of AIDS patients because of social stigma surrounding AIDS. These linkages would also help the transfer of resources (e.g. instrumental, informational, affirmational, and emotional support) from the mediating structures to the self-help groups as well as individual caregivers.

The combination of these several strategies can result in a more comprehensive ecological approach to promoting health of informal caregivers and the community.

### **Limitations and Future Directions for Research**

One of the basic limitations of this study is the bias introduced by its focus on only low-income participants due to the non-cooperation of an organization that support middle-income PWHA. The lack of comparison between different income groups limits the generalisability of caregiving and support experiences.

Although being a member of a cultural group one is studying has some advantages, such as language, this might have limited my ability to explore issues that I might have taken for granted. As an outsider, one can explore issues up to the hilt of participant's experiences.

Also, recruitment of participants through organizations that were providing support services brought its own biases. One, participants might have felt obliged to comply with my request, fearing withdrawal of support by the organizations. Second, this strategy resulted in the recruitment of participants that were receiving some form of support. A more balanced sample including participants that were not attached to any organization might have enhanced the elicitation of a wide range of caregiving experiences, support flows as well as coping strategies.

All interviews were conducted in *Shona*, the native language all participants could speak fluently. The biggest challenge, therefore, came at the translation stage. Throughout this process, I tried to be as objective as possible, in order that what was conveyed in *Shona* got translated into English without putting in words that would convey concepts that I might have wanted to hear. However, there are some concepts that are just not translatable in a manner that captures the original meaning. This is one other possible way bias might have been introduced into the final data.



The use of individual in-depth and semi-structured interviews, complemented by observations contributed to the richness of the data in this study. In the future, however, group interviews (i.e. focus groups) would provide an opportunity to validate and clarify themes from individual interviews. This strategy would also have the benefit of allowing people to talk about issues surrounding taboo areas, such as revealing one's serostatus, fears of contracting AIDS and stigmatisation.

There is little empirical information from the African region on the interactions between poverty and social support, culture, social support and AIDS, social support and health, or other analyses that give weight to inter-country comparisons. As one way of raising the profile of poverty, social support, AIDS and ill health, and the devastation of people, research studies should be undertaken to provide such needed evidence.

Rigorous data are also needed in order to identify the exact mechanisms that help to reduce stigma. To this end, the development of widely accepted indicators to measure changes in stigmatising attitudes would be ideal.

Also beneficial are longitudinal studies that capture the dynamic processes of: reciprocity and obstacles to mutuality, support needs and the types of support that are beneficial to caregivers as dictated by the stages of illness and social reactions.

The adoption of the policy implications suggested above, that favour marginalized groups, is likely to result in people driven and demand responsive intervention projects and actions. The processes involved in such projects would need to be documented to form learning opportunities for others. Such intervention research could take the form of participatory research, in order to enhance the capacities and community competence and efficacy of marginalized groups.

### **Personal reflections on the research experience**

This fieldwork was an intensely poignant experience that left my imagination crushed by the burden of abject poverty, burden of care, desperation, and feeling of powerlessness experienced by family caregivers of AIDS patients, the majority of whom were women (88%, n=24). The most painful part of the fieldwork was therefore, to get into a home for an interview and getting told that there is only food for the next meal, or



nothing at all! Or seeing an emaciated patient sleeping with only one old blanket on top and one underneath.

The enormity of the problem of the AIDS pandemic was also amplified for me by the fact that in each family that had an AIDS patient, there were either one or more close relatives, in most cases the spouse of the patient that had already died of AIDS. Also disheartening was the number of contemporaneous patients under the care of some caregivers. The highest number of family patients per caregiver was three. This was a caregiver looking after three of her siblings, whose fourth sibling passed on (from AIDS) just a month prior to this study. Death was frequent among patients, making this fieldwork an experience filled with grief. One died after the first interview, two after the second, and three after all the interviews had been completed. Therefore, throughout the entire fieldwork, I would unavoidably ruminate on these misfortunes as well as go through a grieving process together with caregivers, as well as during the reconstruction of field notes.

With a training in the social sciences where emphasis is put on objectivity, emotionless involvement and value freedom, I found myself trying, but unsuccessfully trying to always check my emotions in the face of such crushing human suffering. Being a man also compounded the problem, for men are socialised not to wear their emotions on their sleeves. Transcription was also one of the most difficult processes of the study; because everything was played back over and over, bringing back to life the experiences I thought I had at least left behind for a while. It was also difficult in the sense that some concepts are not easily translatable into English without losing some local nuances.

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## Notes

1. Cohen (2000: 7) looks at poverty as a process, and has coined this process immiseration. Here is how he describes the process of immiseration, in relation to AIDS, in Africa:

*Poor families have reduced capacity to deal with the effects of morbidity and mortality than do richer ones for obvious reasons. These include the absence of savings and other assets which can cushion the impact of illness and death. The poor are already on the margins of survival and thus are also unable to deal with the consequent health and other costs. These include the costs of drugs when available to treat opportunistic infections, transport costs to health centres, reduced household productivity through illness and diversion of labour to caring roles, losses of employment through illness and job discrimination, funeral and related costs, and so on. In the longer term such poor households never recover even their initial level of living as their capacity is reduced through the losses of productive family members through death and through migration, and through the sales of any productive assets they once possessed.*

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## APPENDIX A

### Information Letter for Caregivers

Title of Project: Experiences of Social Support Among Family Caregivers of AIDS Patients: A Zimbabwean Case Study

Principal Investigator: Edward Makwarimba

Centre for Health Promotion Studies,  
5-10 University Extension Centre,  
University of Alberta, Edmonton, AB  
Canada T6G 2T4

Phone: (780) 492 - 8048

The reason for doing this study is to look into the type of help those family members who care for people with AIDS get. This help might be from relatives, friends, government or other organizations. We need to know if these people are happy with this help. To enable us to get this information we need permission to talk to family members who care for someone with AIDS. Information from this study is to help me to complete my university education. The information will also be given to the government and organisations that help people who care for those with AIDS. We hope they will use this information to give these people the type of help they need so that they can give better care to their sick relatives.

We are therefore asking for 3 to 4 hours of your time to ask about what you think about the help you are getting from friends, relatives and the government. We will also need to listen to your experiences with caring for your relative. We therefore need to visit you on three different days. These must be days that you are free and can manage to talk to us.

If possible we would like to conduct these discussions at your home where you care for your patient. This is so that we can observe and understand, how exactly you go about helping your patient, the kind of help you get from home based care workers and other people close to you. Therefore, we are also asking for permission to record the way things happen as you give help to your patient as well as get help from those who help you. We are also asking for your permission to record our questions and your answers to make it easier for us to write a good explanation of your experiences when we go back.

This study might not help you with caring for your patient. But if those who are in charge of providing help to the community can use the information we are going to obtain, it might help them to provide required help to families that care for those with AIDS in the near future.

Your taking part in this study might result in problems between you and your spouse or parents, therefore, we would ask you to ask permission from them so that they know what we are doing. After asking for this permission if something goes wrong, we will refer you to local authorities so that you can get some help. You taking part in the study might also result in emotional disturbances. If this should happen, we will try to refer you to the nearest health center for counselling.



We are not going to use your name when we write our report. Any information that might lead to people knowing that you took part in this study will be left out of the report. No one else will be able to listen to the tapes that we are going to use. This information will be kept in a secure area (accessible only to the research team) at the University of Alberta for five years after the study. If further analysis of the data is conducted with the study, further ethics approval will be sought first.

You have the right to refuse to take part in this study. During the interviews, you can choose not to answer any question. You are also free to withdraw from the interview or study at any time. But your taking part in the study will help to improve the kinds of help given to people that care for those with AIDS. *For taking part in this study, you will be given 2 pairs of gloves, a disinfectant, and \$200. If for any reason you choose to withdraw after the study has started, or fail to complete the study for some other reason, you will still receive these items and money.* In case you have any questions about this study, you may contact me at.....or .....at: (name & number of official from institution facilitating contacts).



## APPENDIX B

### Consent form for Caregivers

Title of Project: Experiences of Caregiving and Social Support Among Family Caregivers of AIDS Patients: A Zimbabwean Case Study

Principal Investigator: Edward Makwarimba

Centre for Health Promotion Studies,  
5-10 University Extension Centre,  
University of Alberta, Edmonton, AB  
Canada T6G 2T4  
Phone: (780) 492 - 8048

#### **To be completed by the research participant:**

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and inconveniences involved in taking part in this research study? Yes No

Do you understand that you will be getting \$200, gloves and a disinfectant for taking part in this study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your relationship with the organization that supports your patient. Yes No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

This study was explained to me by: \_\_\_\_\_

I agree to take part in this study.

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date



## APPENDIX C

### **Information Letter for Home-based Care Workers and Community Nurses**

**Title of Project:** Experiences of Caregiving and Social Support Among Family Caregivers of AIDS Patients: A imbabwean Case Study

**Principal Investigator:** Edward Makwarimba

Centre for Health Promotion Studies,  
5-10 University Extension Centre,  
University of Alberta, Edmonton, AB  
Canada T6G 2T4  
Phone: (780) 492 - 8048

The reason for doing this study is to look into the type of help those family members who care for people with AIDS get. This help might be from relatives, friends, government or other organizations. We need to know if these people are happy with this help. To enable us to get this information we need permission to talk to family members who care for someone with AIDS as well as home-based care workers and community nurses who work in the community.

Information from this study is to help me to complete my university education. The information will also be given to the government and organisations that help people who care for those with AIDS. We hope they will use this information to give these people the type of help they need so that they can give better care to their sick relatives.

We are therefore asking for about an hour of your time during which we would like to interview you in order to know more about the ways in which you help these families and your experiences of providing this help. With your permission, we would also like to record our discussion on tape.

We will also be making observational visits to homes of caregivers. During these times, with your permission, we will be interested in observing the interaction between you and the family caregivers, as well as noting what kind of help you provide and how you do it. We also ask for your permission to record those interactions.

This study might not help you with providing help to caregivers immediately. But if organizations like the one you work for use the information we are going to obtain, it might help them and you to provide required help to families that care for those with AIDS in the near future.

We are not going to use your name when we write our report. Any information that might lead to people knowing that you took part in this study will be left out of the report. No one else will be able to listen to the tapes that we are going to use. This information will be kept in a secure area (accessible only to the research team) at the University of Alberta



for five years after the study. If further analysis of the data is conducted with the study, further ethics approval will be sought first.

You have the right to refuse to take part in this study. During the interviews, you can choose not to answer any question. You are also free to withdraw from the interview or study at any time. But your taking part in the study will help to improve the kinds of help given to people that care for those with AIDS. In case you have any questions about this study, you may contact me at....., or....., at.....: (name & number of official from institution facilitating contacts).



## APPENDIX D

### **Consent Form for Home-based Care Workers**

**Title of Project:** Experiences of Caregiving and Social Support Among Family Caregivers of AIDS Patients: A Zimbabwean Case Study

**Principal Investigator:** Edward Makwarimba  
Centre for Health Promotion Studies,  
5-10 University Extension Centre,  
University of Alberta, Edmonton, AB  
Canada T6G 2T4  
Phone: (780) 492 - 8048

**To be completed by the research participant:**

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and inconveniences involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your relationship with the organization that supports your patient. Yes No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

This study was explained to me by: \_\_\_\_\_

I agree to take part in this study.

\_\_\_\_\_  
Signature of Research Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

\_\_\_\_\_  
Signature of Investigator or Designee

\_\_\_\_\_  
Date



## APPENDIX E

### Demographic Questionnaire

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ Participant Number: \_\_\_\_\_  
DD MM YYYY

#### Background Questions

1) Gender of participant:  0. Male  1. Female

2) DOB (dd/month/yr) : \_\_\_\_\_ Age \_\_\_\_\_

3) What is your marital status?  
 1. Single (never married)  3. Widowed  5. Separated  
 2. Married  4. Divorced  6. Common law

4) Number of children  
 1. None  2. One  3. Two  4. Three  
 5. Four  6. More than four

4) What is your highest level of education?  
 1. Grade 7 or less  
 2. Some high school  
 3. Completed high school  
 3. Trade or technical certificate/diploma  
 4. University undergraduate degree  
 5. University graduate degree

5) What is the language most often spoken at home? \_\_\_\_\_

6) What is your occupation? \_\_\_\_\_

7) What is your current employment status (mark all that apply).  
 1. Working full-time  
 2. Working part-time  
 3. Student  
 4. Homemaker  
 5. On sick leave



- 6. On workers' compensation
- 7. On unemployment insurance
- 8. On disability plan
- 9. Retired from work
- 10 Unemployed

8) Are you receiving income from: (check off all that apply).

- 1. Full time employment
- 2. Irregular, casual, or seasonal employment
- 3. (Un)Employment Insurance
- 4. Family Benefits
- 5. Welfare/Social Assistance/SFI
- 6. Disability Pension
- 7. Other (specify) \_\_\_\_\_

9) What is your approximate household income before deductions from all sources?

- 1. Below 5,000
- 2. 5,000 – 9,999
- 3. 10,000 – 14,999
- 4. 15,000 – 19,999
- 5. 20,000 – 39,999
- 6. 40,000 – 59,999
- 7. 60,000 and above

10) All together, how many people live on this income? \_\_\_\_\_

11) Where do you live?

- 1. House
- 2. Apartment or condominium
- 3. Seniors complex
- 4. Seniors lodge
- 5. Nursing home/Auxiliary
- 6. Other (specify) \_\_\_\_\_

12) Do you:  0. rent or  
 1. own the place?

13) Number of Cattle, goats, chickens.



14) If you have land for agriculture, what was your harvest last season?

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15a) How much did you sell? \_\_\_\_\_

b) How much did you keep? \_\_\_\_\_

16) Did you plant anything this season? \_\_\_\_\_

.....



## APPENDIX F

### **Guiding Question for Primary Caregivers (Unstructured interviews)**

**Major Question:** You have been caring for your ..... [relative] for ..... years/months now. I would like you to explain to me your caregiving experience, the good and the bad, from sunrise to sun set up until the following day. (This will go uninterrupted except for the occasional request for clarification.)

Follow up question: I would also like you to tell me the kinds of help you get from relatives, friends, neighbours and any organisation(s) that help you from day to day. I especially need to know the types of help you get, how helpful they are and what types of needs you think are unmet. (The phrasing of this question will depend on how much is felt to be left out in response to the major question. Where a participant appears not to volunteer enough information, more probes will be initiated.)



## APPENDIX G

### Guiding Questions for Primary Caregivers (Semi-structured interviews)

A) What does support mean to you?

After which ➔

Preamble:

In this interview we are going to be talking about support. Support can be given in many different ways. It can be help with material things, like money or helping you with errands while you look after your patient. It can be help with information, advice, or ideas that help you understand things that are going on around you or seek necessary help. It can also be emotional help, a shoulder to cry on, etc. Therefore, when I ask for information concerning how you are helped or how you help, I would like you to keep all these types of help in mind.

### General Questions

- 1) Before you started caring for your....., did you have any experience caring for the sick? Particularly someone with the same health problem?
- 2) If you ever took your ..... to the hospital/doctor, did you ever get told what the problem is?
- 3) When the patient was discharged, did you ever receive any information about how to care for them?
  - If not, did you ever ask for it?
  - If yes, did you have to ask for it?
  - Do you feel like you need any/further information right now?
- 4) How long (in hours) does it take to care for the patient in a day, particularly when they are not feeling too good?
- 5) Which tasks do you do for your patient that take up a lot of your time?
- 6) Which are the physical problems of the patient do you have most difficulty dealing with?
- 7) Do you prepare food separately for your patient? If so, why?
- 8) How much time does it take to access the nearest health facility from your home?
- 9) How many times have you been to a health facility with the patient since they got ill?
- 10) How many times have you been to a health facility yourself in the past 3 or so months?
- 11) Have you taken your..... to a traditional healer since they got ill?
- 12) Have you taken your ..... to a faith healer since they got ill?



## **Available Support**

\* Who do you usually go to when faced with problems regarding your role as a caregiver?

### Partner Support

1. Does your husband/wife/partner always take the time to talk over your caregiving and other problems should you want to?
2. Is she/he always there when you need her/him?
3. In what ways is she/he most helpful and supportive?
4. Which help does she/he give that is related to your caregiving duties?
5. Which help does she/he give that is related to your other responsibilities?

### Friends Support

1. Do you have any close friends with whom you can always talk over your problems?
2. Do your friends care about you?
3. Are your friends always there for you if you should need them?
4. In what ways are your friends most helpful?
5. If they are not helpful, why is this?
6. Do you go out to ask for their help? If not why is this?
7. Do you help your friends when they need your help?

### Relatives Support

1. Are you close to your (maternal and paternal) relatives?
2. Do you think your relatives care about you?
3. Do you have relatives that always take the time to talk over your problems? Which ones are these?
4. Are your relatives always there if you should need help?
5. In what ways are these relatives helpful?
6. Do you have to ask for their help all the time? If so, how does this make you feel?
7. Do you feel that the help they give is adequate? Do you feel good about this?
8. If they are not helpful, why do you think this is the case?
9. Are there any relatives that you also help in any way? How?
10. Do they feel good about this?

### Neighbours Support

1. Do you get along with your neighbours?
2. Are they always supportive and helpful? In what way?
3. If so under what circumstances?
4. Do you always have to ask for their help?
5. Do you think they are supportive enough?
6. Do you also help your neighbours? In what way? Do they come to you with their problems?



### Formal support

1. Which organisations do you normally go for help? How often?
2. What type of help do you get from each of them?
3. Do you find this support helpful to you?
4. Is some of the support given directly to your patient?
5. What particular times do you wish you could have help?
6. What type of help is particularly helpful?

### **Received Support**

1. During the past month, has anybody made you feel that they are very close to you?
2. During the past month, how often have other people listened to your personal problems regarding your responsibilities as a caregiver?
3. First of all I would like to know whom you confide in when you have got intimate personal problems on your mind (or you feel lonely) and you need someone to talk to. Who is this, or who are these people?
  - During the last month, which of these people did you actually talk to about things that were personal and private?
  - or things related to your caregiving role?
4. Can you think of a particularly stressful episode in the past month.
  - a) Who came to help you?
  - b) How much did each of these persons make you feel he/she cared about you?
5. At times we want someone to listen to our concerns and feelings, particularly your concerns about caregiving and related issues. How often does your husband/wife/partner/parents, friend, etc. listen to you in the past three months?
6. At times we want someone to do more than listen to us. We want them to understand our situation and empathize with our feelings.
  - a) How often did your wife/husband/partner/friend, etc. understand and sympathize with you in the past three months?
  - b) Have you ever had personnel from any supporting institutions empathize with you?
7. Which people in your social network give you the chance to talk about how you feel and concerns about your [patient] daughter/son/husband/wife, etc.?
8. Which people in your social network show that they understand what it is like to care for someone who has this kind of medical condition?
9. From your experience, do you find that the support offered by people (relatives or neighbours) is dependant on the type of illness they have?

.....



## APPENDIX H

### **Guiding Questions for Community Nurses and Home-based Care Workers**

1. What are your primary responsibilities in the community?
2. Which categories of health problems are more pressing and demand more of your time?
3. What are your responsibilities regarding people with HIV/AIDS and their families?
4. Do you always find adequate time to satisfy demand?
5. How do you take into their needs and concerns in order that your services are most beneficial?

.....













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